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Perceptions of Determining Factors:  
A Case Study of Eviction Risks of People Who Hoard in Waterloo Region

By

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BA (Hons.), Women's Studies, McGill University, 2006

**THESIS**

Submitted to the Faculty of Social Work  
in partial fulfilment of the requirements for

Master of Social Work

Wilfrid Laurier University

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## ABSTRACT

Recently distinguished as a distinct disorder in the DSM-V, hoarding remains a behaviour about which we have only a cursory understanding. Hoarding behaviours can lead to a variety of health and safety risks, not only for the person who hoards, but for others who live with them, and their neighbouring community. Many studies make reference to the vulnerability of people who hoard as a result of these health and safety risks. However, there has been little written about eviction specifically due to hoarding. This study explores the research question: what factors enable individuals who hoard to maintain their housing when they are potentially at risk of being evicted? A case study methodology has been used to examine the context of eviction in Waterloo Region, Ontario, Canada. Qualitative interviews were conducted with six people who hoard who have been potentially at risk of eviction, as well as nine key informants who have worked with people who hoard through the eviction process. Interview data was analyzed thematically, and is represented in two global themes: 1) Building a Helping Relationship with People Who Hoard, and 2) Building a Framework within which to Provide Service. A strengths-based perspective and general systems theory help to understand the different levels of intervention that social workers and other types of workers can employ with clients who hoard to ensure more effective and positive outcomes.

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## TABLE OF CONTENTS

	PAGE
LIST OF TABLES	viii
GLOSSARY OF TERMS	1
 CHAPTER 1 – INTRODUCTION	 2
1.1 Rationale of the Study	2
1.2 Purpose of the study	3
1.3 Researcher location	4
1.4 Overview of the thesis	5
 CHAPTER 2 – EMPIRICAL REVIEW	 7
2.1 Definition, Characteristics, Comorbidity, and Prevalence	7
2.1.1 Definition of hoarding	7
2.1.2 Characteristics: insight and motivation	8
2.1.3 Comorbidity and other diagnoses	9
2.1.4 Prevalence of hoarding	10
2.2 Impacts at the Individual, Family and Community Levels	11
2.2.1 Impacts at the individual level	11
2.2.2 Impacts at the family level	11
2.2.3 Impacts at the community level	12
2.3 Risks to the Individual, Family and Community	13
2.3.1 Fire risks	13
2.3.2 Hoarding and the risk of eviction	14
2.4 Treatment, Intervention and Community Responses to Hoarding	15
2.4.1 Clinical treatment and intervention approaches	15
2.4.2 Harm reduction model	16
2.4.2.1 Motivational interviewing	17
2.4.3 Community responses to hoarding	18
2.5 Chapter Conclusion	19
 CHAPTER 3 – METHODOLOGY	 21
3.1 Epistemological Perspective	21
3.2 Theoretical Framework	22
3.2.1 General systems theory	22
3.2.2 Strengths-based perspective	25
3.2. Chosen Methodology	26
3.2.1 Qualitative research	27
3.3 Role of Researcher	29
3.4 Research Design: The Case Study Approach	29
3.5 Procedures	32
3.5.1 Recruitment and sampling	32
3.5.2 Data collection	34
3.5.3 Data collection methods	36

	PAGE
3.5.4 Data analysis	39
3.5.5 Trustworthiness of research	42
3.5.6 Ethical considerations	44
3.5.7 Benefits	46
CHAPTER 4 – FINDINGS	47
4.1 Context of Hoarding in the Waterloo Region	47
4.1.1 Eviction risks for people who hoard in Waterloo Region	49
4.1.2 Other regulations	50
4.2 Level of Clutter Data and Preliminary Environmental Scan Data	53
4.3 Study Findings	57
1. Global Theme #1: Building a Helping Relationship with People Who Hoard	58
1.1 Organizing theme: Treatment of Person	59
1.1.1 Kindness	59
1.1.2 Respect	59
1.1.3 Dismissiveness	61
1.1.4 Aggression, control and power	62
1.1.5 Judgment and non-judgment	64
1.2 Organizing Theme: Nature and Context of Relationship with Professionals	66
1.2.1 Rapport	66
1.2.2 Trust	68
1.2.3 Perception as more than a “hoarder”	70
1.2.4 Stigma and discrimination	71
1.2.5 Supportive relationships and shame	73
1.2.6 Connection and isolation	74
2. Global Theme #2: Building a Framework within which to Provide Service	77
2.1 Organizing Theme: Structure and Guidelines	78
2.1.1 Control over the process and possessions	78
2.1.2 Threats and consequences (fear of eviction)	80
2.1.3 Clear expectations and definitions	81
2.1.4 Deadlines and timeframes	83
2.1.5 Chipping away	85
2.1.6 Limitations of services	86
2.2 Organizing theme: Rights of people who hoard	88
2.2.1 Advocacy	89
2.2.2 Limits of authority	90
4.3 Chapter Conclusion	92
CHAPTER 5 – DISCUSSION AND CONCLUSION	93
5.1 Summary of the Study	93
5.2 Discussion of the Findings of the Study	94
5.2.1 Micro level analysis of individual interactions	96
5.2.1.1 Development of a client-worker relationship	96
5.2.1.2 Understanding insight, resistance and defensiveness	99
5.2.1.3 Building a helping community among people who hoard	100

	PAGE
5.2.2 Mezzo Level Analysis of Services	103
5.2.2.1 Responsibility of services: Clear expectations and control	103
5.2.3 Macro Level Analysis of Policies and Services	105
5.2.3.1 Limitations of services	105
5.2.3.1.1 Limitations of harm reduction approach	106
5.2.3.1.2 Mandated treatments and interventions	108
5.2.3.2 Rights of persons who hoard and limits of authority	109
5.2.3.2.1 Human rights and the duty to accommodate	109
5.2.3.2.2 Rights of people who hoard vs. the rights of others	111
5.3 Limitations of the Study	112
5.4 Implications of the Study	114
5.4.1 Social work practice implications	114
5.4.1.1 Utilizing a client-centered, anti-oppressive, strengths-based perspective	114
5.4.1.2 Hoarding-informed education and advocacy	116
5.4.1.3 Toward a hoarding-informed service for people who hoard	118
5.4 Research and Theory Implications	120
5.5 Impact on the Researcher as a Researcher and Practitioner	122
5.6 Conclusions	123
REFERENCES LIST	125
APPENDICES	
A. Request for Participant Referrals and Information to Agencies, Service Providers and Workers	139
B. Invitation and Information to Participate in a Study (for Participants)	140
C. Invitation and Information to Participate in a Study as a Key Informant	142
D. Informed Consent – Participants	144
E. Informed Consent – Key Informants	149
F. Interview Guide – Participants	154
G. Interview Guide – Key Informants	156
H. Counselling Service List	159
I. Clutter Image Rating Scale (CIR)	160



## LIST OF TABLES AND GRAPHS

	PAGE
Figure 1. Visual Representation of the Levels of Systems in General Systems Theory	24
Figure 2. Eviction Prevention for People Who Hoard at Each Systems Level	95
Graph 1. Thematic Network 1.0: Building a Helping Relationship with People Who Hoard	58
Graph 2. Thematic Network 2: Building a Framework within which to Provide Service	77
Table 1. Ratings of Level of Clutter in Participants' Homes Using CIR	54
Table 2. Average Rating of Level of Clutter in Hoarding Situations as Reported by Key Informants	54
Table 3. Environmental Scan of Hoarding Cases as Reported by Key Informants	56

## GLOSSARY OF TERMS

*By-law officer:* A person who works for the municipality that enforces property standards, such as what possessions can be stored outside the home. Referred to as property standards in some communities.

*Code enforcement worker, agency or official:* Refers generically to fire prevention and by-law or property standards officials.

*Clutter Image Rating Scale:* A tool used to assess the volume of clutter in a home. It is a series of photographs that depict an increasing volume of possessions. See Appendix I

*Comorbidity:* A term used when a person has a second diagnosis, in addition to their primary diagnosis. For example, someone with major depressive disorder may also be diagnosed with a comorbid anxiety disorder.

*DSM-5:* Refers to the *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition. This is the most recent edition of the book, which medical and other professionals use to classify and diagnose psychiatric disorders.

*Environmental Scan:* A brief review and assessment of the external environmental factors that could influence or impact the case.

*Forced clear-out:* When someone who hoards is forced to remove, or someone else forcibly removes, the majority or all of their possessions from their home without their consent. For example, as a result of interventions from fire services due to fire risk.

*Hoarding task force:* A collaboration of different services, such as social services, fire prevention, by-law, the humane society and others, that come together to address hoarding situations in a particular community.

*Holarchy:* A term used in systems theory, which describes concentric organization of social systems” (Dale et al., 2009, p. 9), whereby each system is not only made up of smaller systems, but is nested within a larger system. See page 24 for diagram.

*Housing worker:* used generically to indicate landlords, superintendents, property managers, and support workers of both private and subsidized or supportive housing agencies. Housing workers can work for rental units or condominium corporations.

*Key Informant:* Individuals in the community who have worked with people who hoard in different capacities and who were interviewed for this research project.

*Social service workers:* Refers to anyone working in the human service field.

*Supportive housing:* Subsidized or geared to income housing in which support workers are present and available to assist residents with their needs.

## CHAPTER 1

### INTRODUCTION

#### *1.1 Rationale of the Study*

Recently identified as a distinct disorder in the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.), hoarding remains a behaviour about which we have only a cursory understanding. Hoarding behaviours can lead to a variety of health and safety risks, not only for the person who hoards, but others who live with them, and their neighbours. While many studies make reference to the vulnerability of this population with regards to eviction (Frost, Steketee, & Tolin, 2011; Turner, Steketee, & Nauth, 2010; Whitfield, Daniels, Fleasaker, & Simmons, 2012), there has been little written specifically about eviction due to hoarding.

People who hoard severely are vulnerable to eviction or losing their housing as a result of the deteriorating state of their households. Deterioration can be due to the volume of clutter in their homes which can lead to a variety of fire hazards such as blocked exits, flammable materials being piled near stoves or furnaces, or the volume of clutter making the fire difficult to control (Frost, Steketee, & Williams, 2000). Deterioration can also be due to public health hazards, such as rodent and insect infestations, or mould (Bratotiis, 2012), which can also cause people who hoard to be vulnerable to eviction. Considered to be a behaviour that is difficult to stop, social services, code enforcement officials, and housing workers struggle with how to address hoarding (Bratotiis, 2012). A harm reduction approach with an emphasis on safety, rather than discarding possessions or treatment is being promoted in some Canadian communities as an effective method of helping people who hoard to live more safely in

their homes (K. Hodder, personal communication, February 13, 2014; Richter, 2013; Seniors Association of Greater Edmonton, 2013).

## ***1.2 Purpose of the Study***

The purpose of this study is to explore factors that protect against eviction and loss of housing for people who hoard in Waterloo Region, Ontario. The central research question addressed is: *what factors enable individuals who hoard to maintain their housing when they are potentially at risk of being evicted?* This question allows participants to discuss all possible contributing factors—both positive and negative—such as support from counselling or a social service worker, or the threat of an inspection from fire services or public health. The question was designed with a pragmatic paradigm (Creswell, 2014) in mind, wishing to form practical solutions for a problem faced by those who hoard in Waterloo Region. General systems theory is used as a theoretical framework by which to understand the interactions between individuals and the social systems to which they belong. Additional areas of questioning considered include:

- What protective factors have motivated the greatest change in hoarding behaviours?
- Which protective factors, if any, have changed hoarding behaviours over the long-term?
- What factors have been detrimental in attempting to maintain housing, or exacerbated the situation resulting in eviction?

This qualitative case study is centered primarily on intensive interviews conducted with six people who hoard who are, or have been, potentially at risk of eviction. To add further dimension to the study, interviews were conducted with nine key informants from

a variety of social service, code enforcement agencies, housing workers, and private services who have worked in the eviction process.

In addition, the study includes a quantitative component in the form of numerical data that was collected in two forms: 1) an environmental scan from key informants to gain a sense of the prevalence of hoarding in Waterloo Region; and 2) an assessment tool to better understand the participants' degree of hoarding. This study addresses gaps in the literature in two respects. Firstly, given that there are few qualitative studies on hoarding, this study will give voice to people who hoard within the literature. Secondly, this study addresses eviction prevention and how professional intervention impacts this vulnerable population in maintaining their housing.

### ***1.3 Researcher location***

Having worked in the private sector as a professional organizer for over two years in Toronto, Canada, I became aware of gaps in services available to assist individuals who hoard. At a 2013 Toronto workshop I attended, participants from across southern Ontario expressed their concern over the lack of community resources that were available to assist with hoarding situations. As a professional organizer, I received calls from people in distress, saying, "I think I'm a hoarder and I don't know what to do." I did not know of any social or mental health services that could address the issue locally, especially ones that were affordable.

My work in the non-profit sector with marginalized people, as well as my background in women's studies with a focus on social justice have both informed my perspective on this issue. I believe the issue of housing security and access to housing is

a vital one, particularly in the face of growing income disparities in Canada. As a result of my education and experiences, I believe there is need for research that includes the voices of the people whom it purports to help. The practical implications of this study are at the forefront of my motivations: 1) to identify both gaps in existing services in Waterloo Region; and 2) to identify other factors that could be promoted or utilized in the future to prevent the eviction of people who hoard.

#### ***1.4 Overview of the thesis***

This thesis is divided in five chapters. The first chapter presents an introductory outline of the study. The second chapter outlines the pragmatic paradigm and theoretical framework taken, and reviews current literature on hoarding. I first explore the prevalence of this behaviour and links to different diagnoses. I also review the issue of insight and motivation, and the impacts of hoarding on the community, including the risks, costs, and the correlation with eviction. Finally, I survey the community response to hoarding and treatment and intervention approaches. In chapter three I describe the methodological approach, reviewing the uses and benefits of qualitative research and the case study approach, and outlining in detail the steps taken in this study. In chapter four I outline the findings of this study. I first provide a brief overview of the context of Waterloo Region and eviction due to hoarding, as well as other factors that can lead to loss of housing. I analyzed and organized the data thematically, and included thematic maps provide a visual representation of the findings and their organization. In chapter five I provide a discussion of the findings, outlining areas needing further investigation and the practice implications of this study. Topics discussed are divided into micro,

mezzo and macro systems levels, depending upon the interaction between the individual and the larger community, services and culture. I have written a brief conclusion to summarize this study, and its implications. It is my hope that this research will help to address some of the gaps in services that exist for people who hoard, providing a roadmap for people who work with individuals who hoard to better understand the perspectives of the people with whom they are working, and how to best help in preventing eviction. Through this study, I explore my research question, seeking factors that have enabled individuals who hoard to maintain their housing when they have been at risk of eviction.

## CHAPTER 2

### EMPIRICAL REVIEW

In this chapter, I outline the existing literature and research on hoarding behaviours. I begin by defining hoarding, describing the comorbidity and other possible diagnoses, and reviewing the literature as to the prevalence. Given this study has been informed by systems theory (described in further detail in Chapter 3), I then discuss the impact of hoarding at the individual, family, and community levels. I have followed with a discussion of the risks that hoarding poses to the individual, their families and the surrounding community. Finally, I provide an outline of the clinical treatments and interventions, as well as the community response to hoarding.

#### ***2.1 Definition, Characteristics, Comorbidity, and Prevalence***

##### ***2.1.1 Definition of hoarding***

Much of the existing literature on hoarding is rooted in a cognitive-behavioural model developed by Frost and Hartl (1996). Frost and Hartl (1996) propose that hoarding stems from four cognitive-behavioural problems: information processing deficits; problems forming emotional attachments; behavioural avoidance; and erroneous beliefs about the nature of possessions. In this defining piece of literature, the authors propose a definition for compulsive hoarding:

(1) the acquisition of, and failure to discard a large number of possession that appear to be useless or of limited value; (2) living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed; and (3) significant distress or impairment in functioning caused by the hoarding. (Frost & Hartl, 1996, p. 341)



This provided a definition of hoarding from which workers have operated for a number of years. However, hoarding has garnered attention from a diagnostic perspective, and has subsequently been listed distinctly as Hoarding Disorder (HD) in the *DSM-5*. The criteria for HD in the *DSM-5* is listed as:

- A. Persistent difficulty discarding or parting with possessions, regardless of their actual value.
- B. This difficulty is due to a perceived need to save the items and to distress associated with discarding them.
- C. The difficulty discarding possessions results in the accumulation of possessions that congest and clutter living areas and substantially compromises their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, authorities).
- D. The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment for self and others).
- E. The hoarding is not attributable to another medical conditions (e.g., brain injury, cerebrovascular disease, Prader-Willi syndrome).
- F. The hoarding is not better explained by the symptoms of another mental health disorder (e.g., obsessions in obsessive-compulsive disorder, decreased energy in major depressive disorder, delusions in schizophrenia or another psychotic disorder, cognitive deficits in major neurocognitive disorder, restricted interests in autism spectrum disorder) (American Psychiatric Association, 2013, p. 247).

While changes have been made, the definition retains much of the same criteria as originally proposed by Frost and Hartl (1996).

### *2.1.2 Characteristics: insight and motivation*

Literature on hoarding generally accepts that there is both a “lack of insight” and low motivation to change in people who hoard (Bratton, Sorrentino Schmaslisch, & Steketee, 2011; Frost et al., 2011; Frost, Tolin, Steketee, Fitch, & Selby-Burns, 2009; Grisham, Steketee, & Frost, 2008). However, little research has been done specifically on this topic, and authors Worden, DiLoretto and Tolin (2014) identify the lack of differentiation between insight and motivation as problematic. Frost, Tolin and Maltby

(2010) distinguish three specific areas of insight that can lead to problems: anosognosia or lack of awareness about the problem; overvalued ideation regarding the worth or value of possessions; and defensiveness around discarding items or problematic behaviour.

Discussion about insight continues to propagate the deficit-laden language and assumptions about people who hoard. Frost et al.'s (2010) differentiation between types of insight; however, can be used to understand the discrepancy between worker (service provider) and client understanding about the problematic nature of hoarding.

### *2.1.3 Comorbidity and other diagnoses*

Previously listed in the *DSM IV-TR* as a symptom or behaviour resulting from Obsessive-Compulsive Personality Disorder (OCPD), as well as a possible symptom of Obsessive Compulsive Disorder (OCD) (Mataix-Cols & Pertusa, 2012; Rachman, Elliott, Shafran, & Radomsky, 2009), hoarding has most frequently been tied to OCD. In the *DSM-5*, HD is listed under OCD and Related Disorders, also a new section of the *DSM-5* (Mataix-Cols & Fernández de la Cruz, 2014). However, studies have shown that fewer than 20% of people with hoarding disorders also have OCD (Frost et al., 2011), and only a small number of people, between 11 and 30%, with OCD also hoard (Rachman et al., 2009). Recent literature proposes that 25-30% of people with OCD also have comorbid HD, and a corresponding 10-15% of people with HD have comorbid OCD (Wheaton & Van Meter, 2014). An important consideration for the creation of a separate diagnostic category for HD was the poor treatment outcomes of people with hoarding symptoms in OCD samples, suggesting that a novel treatment was needed (Mataix-Cols & Fernández de la Cruz, 2014).

The high rate of comorbidity associated with hoarding, and large number of other diagnoses from which hoarding behaviour can stem, led early researchers to posit that hoarding was a symptom rather than a diagnosis unto itself (Greenberg, Witzum, & Levy, 1990 in Damecour & Charron, 1998). Pertusa and Fonseca (2014) outline a wide array of possible diagnoses that could result in hoarding behaviours: OCD, OCPD, schizophrenia, dementia and neurodegenerative disorders (including severe domestic squalor, Alzheimer's, Parkinson's and Huntington's diseases), affective disorders (such as anxiety), traumatic life events, mania, depression, learning disabilities (such as pervasive developmental disorders, and genetic disorders), and acquired brain injury. However, the authors note that it is possible that any of these diagnoses could be comorbid with a diagnosis of HD rather than the cause of the hoarding behaviour (Pertusa & Fonseca, 2014). Similarly, anxiety disorders, depressive disorders, bipolar disorders, impulse control disorders, attention-deficit/hyperactivity disorder, and personality disorders have also been found to be comorbid with HD (Wheaton & Van Meter, 2014). There is speculation that comorbid HD complicates treatment, however, given that much of the research on comorbidity is preliminary further investigation is required (Wheaton & Van Meter, 2014).

#### *2.1.4 Prevalence of hoarding*

Lack of clarity about the precipitating factors and diagnosis of hoarding has allowed this condition/behaviour to go untreated and often undetected. It is estimated that between 2 and 6% of the general population hoard (Meyer, Frost, Brown, Steketee, & Tolin, 2013; Samuels *et al.*, 2008), although given the recent addition of hoarding as a distinct disorder to the *DSM-5* and the often hidden nature of this behaviour, accurate

numbers are difficult to estimate. Mataix-Cols and Fernández de la Cruz (2014) suggest that further research may demonstrate a more appropriate classification for HD within the *DSM-5* pending further research.

## ***2.2 Impacts at the Individual, Family and Community Levels***

### ***2.2.1 Impacts at the individual level***

Hoarding impacts the individual who hoards in many different ways. Tolin et al. (2008) studied the impact of hoarding in a group of 864 people who self-identified as hoarding, as well as 665 people who had family members who hoard. Their study revealed several findings regarding the impact on employment and the personal finances of people who hoard. Participants who met the diagnostic criteria for hoarding missed an average of seven workdays in the preceding month, and 6% reported having been fired from jobs due to hoarding (Tolin et al., 2008). Additionally, 7% of participants were receiving disability benefits, and 38% had an income below the poverty line for a single person in the United States; more than one fifth had not filed a tax return in at least one of the past five years (Frost et al., 2008). The literature demonstrates the possible effects hoarding behaviour can have on an individual, particularly with regards to employment and income.

### ***2.2.2 Impacts at the family level***

The experiences of family members of people who hoard has been reported as overwhelmingly negative in the literature (Sampson, 2013; Tolin et al., 2008; Wilbram, Kellett, & Beail, 2008). Drury et al. (2014) reported that the levels of burden experienced in developmental, social and emotional areas by family members of people who hoard

exceeded those of family members of people with Alzheimer's. According to the family members of people who hoard, as many as one in 25 people had a child, elder or pet removed from the home due to hoarding conditions (Tolin et al., 2008). The negative impact of hoarding on family members may lead to a lack of involvement in helping to maintain the home in cases where code enforcement agencies are involved; McGuire et al. (2013) found that 51% of cases reported to code enforcement agencies did not have family involvement.

### *2.2.3 Impacts at the community level*

The community costs of hoarding have well been documented. In an effort to address the safety risks often caused by hoarding, some communities have attempted to clear out the homes of people who hoard. This has proven to be not only expensive but also ineffective in the long-term, as most people who hoard will simply re-accumulate possessions at an alarming rate following a forced clear-out (Bratitotis, 2012). One health department spent \$16,000 on a clear-out, only to find the clutter re-accumulated within a year (Frost, et al., 2000). A study of social service staff and code enforcement agencies reported that the average cost for clutter removal was in excess of \$3,700 per hoarding case (McGuire, Kaercher, Park, & Storch, 2013). However, the authors note that this estimate only addresses the physical clutter and does not include caseworker time, landlords' costs, legal fees and other costs, which would increase expenditures significantly (McGuire et al., 2013). The same study revealed that more than one-third of the cases reported required more than a year to resolve, and that half of the participants had encountered a "repeat hoarding offender" within the past year (McGuire et al., 2013, p. 338). One community report estimated the annual costs of hoarding between \$2,607

and \$36,880 corresponding to different service delivery methods, with a greater chance of re-accumulation with forced clear-outs (San Francisco Task Force on Compulsive Hoarding, 2009).

### ***2.3 Risks to the Individual, Family and Community***

The accumulated items in the homes of people who hoard can cause significant risks to the individual, to others in the home and to the community at large (Frost et al., 2000). In many severe cases, clutter precludes the individual from basic functions in the home (eg. interfering with moving around in the home, access to furniture, the ability to prepare food and meals, as well as the ability to maintain hygiene) (Steketee, Frost, & Kim, 2001). A study exploring hoarding-related complaints to a Massachusetts health department found that complaints were most common among neighbours (52%) or by the police or fire department (47%), while complaints from social services and service personnel visiting the home were relatively low (19% and 16% respectively) (Frost et al., 2000).

#### ***2.3.1 Fire risks***

One of the most common safety risks associated with hoarding is fire hazard. Fire hazards can affect not only the person who hoards and anyone who lives with them, but also neighbouring homes and the firefighters tasked with putting out the blaze. A report sponsored by the Melbourne Fire Brigade in Australia notes that there may be increased fire risks in homes with hoarding on three fronts: initiating hazards, enabling hazards, and impeding movement (Lucini, Monk, & Szlatenyi, 2009). While less common in hoarding situations, initiating hazards (the source of ignition such as heating or cooking equipment)

can still pose a problem, as anecdotal evidence suggests that households with hoarding “have a higher than average rate of unorthodox use of utilities that may initiate a fire” (Lucini et al., 2009, p. 17). It is common for people who hoard not to want repair people and landlords into the home out of fear of discovery and shame, and makeshift solutions are often improvised when heating or a stove does not work (Kellett, Greenhalgh, Beail, & Ridgway, 2010). Homes with hoarding problems are subject to increased enabling hazards, whereby the volume of clutter in the home can increase the severity of a fire once it starts, and result in the spread of the fire (Lucini et al., 2009). The spread of the fire can be a risk to neighbours, especially in apartment complexes or townhouses where units have shared walls. The volume of clutter within a home with hoarding can impede movement, preventing a person trapped inside from escaping, or preventing access to the home by fire services or emergency personnel (Lucini et al., 2009). There have also been reports of firefighters becoming trapped by the accumulated possessions, which has resulted in both injury and death (Cavaliere & Wulforth, 2014; Sisak & Blinder, 2014; Yimam, 2014,). The authors report that over a 10-year period only 0.25% of fires were in homes with hoarding (Lucini et al., 2009). However, fires in homes with hoarding accounted for “24% of all preventable fire fatalities” (Lucini et al., 2009, p. 43). The authors report that in 38% of these incidents, entrances were sufficiently blocked so as to make it difficult for firefighters to enter the home (Lucini et al., 2009).

### *2.3.2 Hoarding and the risk of eviction*

Given that the deteriorating state of the home can lead to pest infestations and fire hazards, people who hoard may face eviction as a result (Rodriguez et al., 2012). In a study examining the link between traumatic life events, early material deprivation and

hoarding, Landau et al. (2010) demonstrate the prevalence of housing issues in the lives of people who hoard, and found:

Nearly 1 in 5 hoarders experienced a lack of adequate shelter over their life (due to circumstances ranging from eviction and homelessness to living in substandard accommodation), compared to none of the non-hoarding OCD participants and 5% of non-clinical controls. (p. 201)

However, Landau et al.'s 2010 study does not specify the numbers of people who hoard who have been evicted, are or were at risk of eviction, or experienced homelessness as a result of eviction. Tolin et al. (2008) found that 7.8% of the people who hoarded in their sample had either been evicted or had been threatened with eviction; the same study also sampled family members of people who hoard, and of that group 12.5% reported that their family member had been threatened with eviction or had been evicted. The lower numbers reported by people who are hoarding (as opposed to their family members) could be explained by the reluctance of individuals to seek help for their hoarding behaviours, either out of embarrassment or due to viewing hoarding as unproblematic. Meanwhile, a study done in the UK found that up to 21% of newly admitted residents to a Salvation Army shelter had hoarding behaviours, and 8% reported that hoarding had directly contributed to their homelessness (Rodriguez et al., 2012).

## ***2.4 Treatment, Intervention and Community Responses to Hoarding***

### ***2.4.1 Clinical treatment and intervention approaches***

Hoarding disorders are considered difficult to treat (Tolin, 2011b) as well as costly to both service providers and landlords (Tolin, Meunier, Frost, & Steketee, 2011).

Treatment modalities that have been demonstrated to lead to improvements in hoarding



behaviours include both individual and group cognitive-behavioural therapies (CBT) (Gilliam et al., 2011; Sorrentino Schmalisch, Bratitotis, & Muroff, 2010; Steketee, Frost, Tolin, Rasmussen, & Brown, 2010), self-help and support groups (Frost, Pekareva – Kochergina, & Maxner, 2011; Frost, Ruby, & Shuer, 2012; Muroff, Steketee, Himle, & Frost, 2010), and pharmacotherapy (Saxena, 2011). Given that many people who hoard do not feel that the behaviour is problematic, a harm reduction approach could be considered appropriate, particularly as a starting point for treatment (Tolin, 2011a; Tompkins, 2011; Whitfield et al., 2012). Using a harm reduction approach, the primary goal is to ensure the safety of the individual who hoards rather than to eliminate all of the accumulated clutter and cease hoarding behaviours. Given the costliness of CBT treatments, the limited social service resources to which many communities have access, as well as the possibility of clients being unwilling to enter treatment, this approach may help individuals who hoard maintain their housing in the face of possible eviction or loss of housing.

#### *2.4.2 Harm reduction model*

Harm reduction is commonly known and used in treating drug addictions to minimize risks associated with drug use. The approach was popularized in the 1980s as a result of HIV infection among intravenous drug users due to acknowledgement that strategies being used at the time were not only ineffective but were intensifying the problems associated with drug use (O'Hare, 1992). Harm reduction models have proven effective in working with people who may not want treatment in diverse circumstances, including promoting safer sex, binge-eating, and cutting/self-harm (Logan & Marlett, 2010). The goal of harm reduction is centered on minimizing risks associated with the

behaviour until such time that the individual is ready to address changing or stopping the behaviour, although stopping the behaviour is not necessary to continue treatment (Denning & Little, 2012).

Tompkins has written extensively about the application of harm reduction to hoarding situations, including a guide for family members to use a harm reduction approach when working with a loved one who hoards (Tompkins & Hartl, 2009), and more recently, a guide for clinicians (Tompkins, 2015). Tompkins (2015) identifies harm reduction is not a traditional “treatment” in that it focuses on the symptoms (ie. the accumulation of items and resulting health and safety risks) rather than focusing on reducing distress associated with the problem. He suggests that this strategy is effective for working with people who hoard for three reasons: 1) refusal of help by many people who hoard; 2) over-focusing on treatment and/or discarding may exacerbate the hoarding behaviour; and 3) the scope of the problem is often too overwhelming for one person to manage (Tompkins, 2011).

#### *2.4.2.1 Motivational interviewing.*

Motivational interviewing (MI), developed by Miller and Rollnick (2002), is “not a skillful clinical method, a style of counselling and psychotherapy” (p. 35). Rather, MI is a counselling approach that focuses on the promotion of change in issues where the person might not be ready, willing or ambivalent (Miller & Rollnick, 2002). Using Prochaska and DiClemente’s (1984) stages of change model as its basis, MI accepts that people may be at different stages of their readiness to change a problematic behaviour. Originally designed as a method to help promote change in people with addictions, MI also accepts that not all motivating factors in a person’s readiness to change are the result

of therapeutic intervention (Miller & Rollnick, 2002). Tompkins (2015) promotes the use of MI with people who hoard given that people who hoard can be defensive about this behaviour after a lifetime of pressure to change. MI provides a non-confrontational, non-aggressive method by which to help clients achieve change (Tompkins, 2015). While he notes that there are no empirical studies to demonstrate the efficacy of MI as applied to hoarding problems, he suggests “because MI is a respectful, humanistic approach, it is useful for people who are victims of stigmatization of public condemnation” (Tompkins, 2015, p. 102).

#### *2.4.3 Community responses to hoarding*

Due to the complex nature of hoarding, it is common for a multitude of social service, housing, and code enforcement workers to become involved. Given that hoarding can result in high costs, it is imperative that workers across these different services collaborate (Bratitotis et al., 2011). Bratitotis’ (2013) examination of hoarding task forces across the United States found that the participation of different workers in these interdisciplinary teams had a number positive outcomes: enhanced sensitivity to the problems associated with hoarding; assistance with cost containments; increased identification of resources for clients who hoard; the development of practices specific to hoarding cases; improved tracking and monitoring of hoarding cases; and regular staff training and education about hoarding. However, Bratitotis (2013) also notes that task forces often lack permanent funding, and that their continued success is dependent on the willingness of their member agencies to commit time and allocate resources.

Hoarding task forces or committees have begun to spring up across Canada in the past decade. While to my knowledge there is currently no academic literature specific to

the Canadian context, an online search reveals that a number of communities in southern Ontario have developed task forces or committees, including Ottawa (Dinning, 2006), Toronto (Toronto Hoarding Coalition, 2012), Durham Region (Durham Region Hoarding Coalition, 2013), Quinte West (Quinte West, n.d.), London (London Fire, n.d.), Kingston (Stafford, 2011), Barrie (Browne, 2013), Windsor (CBC News, 2014), Hamilton (Kenny, 2012) and Wellington Guelph (Wellington Guelph Hoarding Network, 2015). Most hoarding coalitions or task forces are comprised of people who have full-time positions in social services or code enforcement agencies, and do not have paid staff specific to hoarding situations. At the time of this research, I am aware of only two areas (other than Waterloo Region) that have a full-time staff member dedicated to working with people who hoard. Northumberland County hired an individual through the Northumberland Hills Hospital in 2014 (Northumberland Hills Hospital, 2014). Similarly, the Wellington Guelph Hoarding Response Network was in the hiring process for a coordinator at the time of this research as advertised among local agencies (Y. Bowes, personal communication, March 4, 2015). While services are beginning to become more established, there are still limited resources specific to hoarding in Ontario.

## ***2.5 Chapter Conclusion***

In summary, I have used systems theory as a general framework by which to organize the existing literature on hoarding, which focuses on the individual and mezzo levels. At the individual level, the literature suggests that hoarding behaviour is not limited to people with a diagnosis of HD, but can be caused by a range of other diagnoses, and can be complicated by comorbid conditions. Hoarding behaviours can pose a number

of health and safety risks not only to the individual who hoards, but also to their family and the broader community. At the mezzo level, clinical treatments and interventions have been demonstrated to help reduce hoarding behaviours for some individuals, but treatments are limited both in availability and effectiveness. Moreover, not all people who hoard wish to participate in clinical treatment. As a result, a harm reduction approach, with the input and support from a variety of different service providers and code enforcement agencies is being utilized to address the safety concerns that can result from hoarding and ultimately compromise the housing security of people who hoard.

## CHAPTER 3

### METHODS

#### *3.1 Epistemological Perspective*

Stemming from a desire to see practical and demonstrable change in the area of eviction prevention for people who hoard, the epistemology of this study takes a pragmatic approach. Creswell (2014) explains that this approach “focus[es] attention on the research problem and in social science research and then us[es] pluralistic approaches to derive knowledge about the problem” (p. 11). Given that this research is undertaken as part of a master of social work program and focuses on a real problem that exists in the community (eviction due to hoarding), this approach allows the flexibility to use what works and what is useful, as opposed to a strict adherence to a particular philosophy at the expense of the practical outputs of the study.

Cherryholmes (1992) notes, “Pragmatic research is driven by anticipated consequences” (p. 13); this study has been undertaken with the anticipation that this research will help to create not only a better understanding of the link between hoarding and eviction, but will also generate practical solutions to the issue. With the hope that the ideas, strategies, and interactions that participants outline as useful in maintaining their housing will be applicable to others in the same position, a pragmatic paradigm allows me to focus on what works, selecting a theoretical framework and methodology that seeks concrete answers to the research question.

A pragmatic paradigm is often used as an approach for mixed-methods research (Feilzer, 2010). While this study is qualitative, rather than mixed methods, as a case study also included a quantitative component and I have examined multiple sources of

data, as described in more detail later in this chapter. Therefore, a pragmatic approach is used similarly to that of a mixed methods research design, using both qualitative and numerical data, moving between the traditionally oppositional frameworks of qualitative and quantitative methodologies (Feilzer, 2010).

### ***3.2 Theoretical Framework***

Given the pragmatic perspective taken in this research, I work within several theoretical frameworks to address the multiple levels of functioning that hoarding can impact. Given that hoarding impacts the individual, their families, the broader community, and the social systems, I have primarily used general systems theory as a way to understand these different levels of interaction. However, in understanding and analyzing the data from participants' points of view, I have also utilized a strengths-based perspective. The following sections outline general systems theory and the strengths-based perspective.

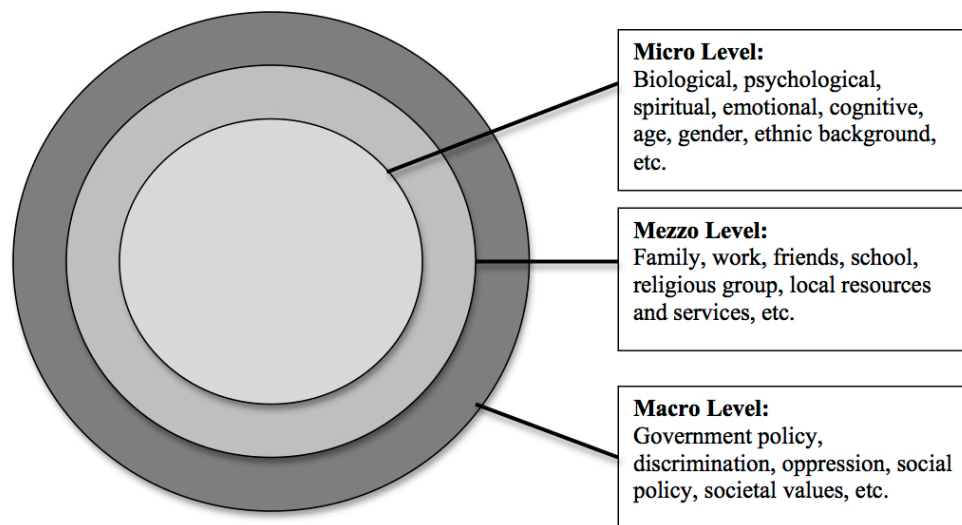
#### ***3.2.1 General systems theory***

General systems theory provides a framework to allow an understanding of the multiple, overlapping, and often competing or conflicting, needs of individuals, groups, and communities involved in hoarding situations. With roots in both sociology and biology, systems theory was introduced to social work in the late 1950s using the name general systems theory, but was not popularized until the late 1970s (Robbin, Chatterjee & Canda, 2012). Social systems theory “is a set of assumptions and concepts that seeks to explain the general patterns of behaviours exhibited by the functioning of social systems and how social systems achieve well-being” (Dale, Smith, Norlin & Chess, 2009,

p. 18). Systems theory understands there to be multiple different systems operating simultaneously at different levels, each interacting and influencing one another. Higher level social systems affect the individuals, and individuals affect the larger social systems within which they exist (Greene, 2008). Systems theory offers an alternative to the historic medical model in which social work has roots (Greene, 2008). Given that much of the existing research that has been done on hoarding exists within a medical framework, systems theory offers a more holistic approach, viewing the individual and their interactions with their environment.

Systems theory understands there to be three different levels at which systems operate. The micro level represents the individual, including “biological, psychological, spiritual, emotional, cognitive, recreational, and financial” factors (Rogers, 2013, p. 23), as well as “factors such age, gender, income, and ethnic background” (Rogers, 2013, p. 23). Meanwhile, the mezzo level “consists of elements in a person’s immediate environment, including family, friends, co-workers, neighborhood, work environment, church activities, local resources and services, and transportation” (Rogers, 2013, p. 23). The broadest level is the macro level, which represents “larger social forces that might affect an individual, such as government policy, discrimination, oppression, social policy, economic conditions, social values and even historical events” (Rogers, 2013, p. 23).





*Figure 1. Visual Representation of the Levels of Systems in General Systems Theory*

Systems theory uses the concept of *holarchy* to understand the interconnected nature of the various systems to which we belong. This term describes “the concentric organization of social systems into even large systems” (Dale et al., 2009, p. 9), whereby each system is not only made up of smaller systems, but is nested within a larger system (see Figure 1). Dale, Smith, Norlin and Chess (2009) outline some of the potential systems within the holarchy, including the individual, family, groups, bureaucracies, communities and society. These various systems interact constantly, transforming both the individual and the larger society (Dale et al., 2009). Significantly, systems theory places importance on the holistic nature of systems, whereby different systems are connected to and influence one another, operating as parts of a whole. Hoarding impacts the individual who hoards, as well as their families, neighbours, broader communities, and social systems. Therefore, systems theory is used in this study as a way to understanding the multiple, intersecting and overlapping interactions between these different systemic levels.

### 3.2.2 *Strengths-based perspective*

Given that much of the existing literature on hoarding uses a medical model as its basis, examining the deficits of people who hoard in a clinical manner, there is a need for research that focuses on the experiences and perspectives of people who hoard. I also use a strengths-based perspective, giving primacy to the voice of the participants who hoard, rather than the workers involved in their cases. A strengths-based perspective takes the position that clients are necessarily a factor in their own healing. Bertolino (2010) writes that a strengths-based perspective is:

[A]n overarching philosophical perspective that sees people as having capabilities and resources within themselves and their social systems. When cultivated, activated, and integrated with new experiences, understandings, ideas, and skills, these strengths help people to reduce pain and suffering, resolve concerns and conflicts, and cope more effectively with life stressors (p.12).

Using this perspective, I value the contributions of participants in this research as central and pivotal in the change process.

As a tool of social work practice, the strengths-based perspective has six foundational principles:

1. Every individual, group, family and community has strengths that precede interventions;
2. Trauma, abuse, illness and other struggles are harmful, and can also provide openings for strengths and resiliency;
3. Practitioners do not know the capacity limits of their clients, and must take their ambitions seriously;
4. Clients are best served through collaboration and a non-expert approach;
5. All environments have resources into which clients can tap;

6. Caring and caretaking must be valued societally (Saleebey, 2009).

As a social work student and practitioner, I have incorporated these principles into the perspective that I take in analyzing participants' narratives and in the discussion of those findings.

Further to this, Sullivan and Rapp (2009) acknowledge that “while systems theory and ecological models may provide excellent templates for understanding human development and behavior, it is decidedly more difficult to use this knowledge to effect desired change” (p. 220). The authors recognize that individuals need to access appropriate resources in order to flourish within systems, and that often clients of social work practice are individuals who are unable to access those resources (Sullivan & Rapp, 2009). The authors note that the loss of participation of those individuals in social systems “thwarts both human and social development” (Sullivan & Rapp, 2009, p. 221). Rather than focusing on absent resources, the strengths-based perspective “promotes matching the inherent strengths of individuals with naturally occurring resources in the social environment” (Sullivan & Rapp, 2009, p. 223). While this research seeks to identify gaps in services, I have also used a strengths-based perspective in promoting resources where participants have identified them.

### ***3.2. Chosen Methodology***

A qualitative research approach and a case study research design were chosen for this research. The exploratory nature of qualitative research was selected given the relatively recent nature of research about hoarding, especially with regards to eviction prevention. A case study research design is “an in depth analysis of a case, often a

program, activity, process or one or more individual” (Creswell, 2014, p. 14). A case study was chosen given the unique nature of Waterloo Region’s services for people who hoard through the newly developed Hoarding Project. Additionally, a case study research design allows for the inclusion of data from multiple sources, giving greater depth and breadth to the types of determining factors of housing maintenance.

### *3.2.1 Qualitative research*

According to Engel and Schutt (2013) qualitative research emphasizes exploratory research questions, such as the one presented here, and remains “committed to inductive reasoning...[and] aim[s] to discover what people think, how they act, and why” (p. 272). Further, Engel and Schutt (2013) write, “qualitative methods have their greatest appeal when we need to explore new issues, investigate hard-to-study groups, or determine the meaning people give to their lives and actions” (p. 272). One might characterize people with hoarding tendencies as “hard-to-study” given the often hidden nature of this problem. Similarly, Yegidis and Weinback (2002) write that case studies are appropriate when the topic involves “a form of behavior that is not socially sanctioned” (p. 139) and when participants may be fearful of being identified. As a result of the social stigma attached to hoarding, this group is indeed reluctant to be identified as such.

Creswell (2014) outlines that within exploratory, qualitative methods, case study research designs are found across many fields where a researcher “develops an in-depth analysis of a case... bounded by time and activity” (p. 14). A case study methodology was selected for this research, allowing the focus on a geographic region, Waterloo Region, with services available specifically to people who hoard through the Hoarding Project. Case study was also selected with the desire to seek potentially replicable results

in other areas of southern Ontario. Additionally, case study methods allows for the exploration of multiple different sources of data to gain a deep understanding of the case in examination. Therefore this research design allows for the inclusion of data from multiple sources and formats, in this instance, from both people who hoard, individuals who work with people who hoard through the eviction process, and an appraisal of the environmental context of these experiences.

This exploratory case study focuses on the intensive interviews of people who are, or have been, potentially at risk of eviction. Intensive interviews are a process whereby participants are asked open-ended questions in a relatively unstructured manner, as the interviewer seeks “in-depth information on the interviewee’s feelings, experiences, and perceptions” (Engel & Schutt, 2013, p. 271). The intensive interviews in this research seek to answer the central research question: what factors enable individuals who hoard to maintain their housing when they are potentially at risk of eviction? Distinct methods of data collection were utilized to answer this study’s research question. Firstly, thick descriptions given by participants as to their experiences around potential eviction risk have provided data that I have analyzed inductively, seeking patterns and thematic commonalities. Secondly, interviews with key informants who are employed to work in the eviction process were analyzed thematically, adding further dimension to participants’ data. Third, numerical data from a preliminary environmental scan demonstrates the prevalence of hoarding cases and establishes a baseline for Waterloo Region. However, this numerical data by no means provides official statistics of the prevalence of hoarding in Waterloo Region.

### ***3.3 Role of Researcher***

The role of the researcher was multi-faceted: working primarily as a researcher and investigator, but in the spirit of social work values, also as an advocate for people who hoard (Canadian Association of Social Workers, 2005). Given both the sensationalist stories of hoarding portrayed in the media<sup>1</sup>, and the lack of knowledge about hoarding, it is paramount that this group be treated in a respectful, sensitive and empathetic manner. I was employed by Supportive Housing of Waterloo (SHOW) for a ten-week period from June through August 2014, during which time I shadowed the Hoarding Project Coordinator on home visits and meetings with clients and case conferences. I gained a better understanding of the issues faced by people who hoard, the services available, and importantly, the rapport-building techniques that enable the Hoarding Project Coordinator to work effectively with her clients. Given that the Hoarding Project Coordinator's role at SHOW is supportive, this experience ultimately allowed me to learn how to develop a trusting relationship with people who hoard, so that they were able to feel comfortable to share deeply personal information about their homes and lives.

### ***3.4 Research Design: The Case Study Approach***

Some scholars consider case studies to be less a specific methodology, than an approach (Hamel, 1993; Stake, 2000). However others (Creswell, 2014; Engel and Schutt,

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<sup>1</sup> Headlines such as “Hoarding issue in fatal Beloit house fire” (McDonald, 2014), “Hoarder Who Shot California Animal Control Officer Found Guilty of Murder” (Daugherty, 2014) and “Dallas spent \$26K removing body, junk from hoarder's home” (Schechter, 2014) contribute to the public perception of people who hoard as dangerous and unstable.

2013; Yin, 2014) identify case studies to be a specific qualitative research design, and outline carefully the steps needed in order to undertake case study methodology (Yin, 2014, Creswell, 2013). Creswell (2013) defines case studies as the investigation of “a real-life, contemporary bounded system (a case) or multiple bounded systems (cases) over time, through detailed, in-depth data collection involving multiple sources of information” (p. 97). Stake (2000) states, “Case study is... a choice of what is to be studied” (p. 435), explaining that case studies often consist of multiple and differing methodologies, as long as it is concentrated on a particular case, as this research is with its focus on Waterloo Region. In keeping with a pragmatic worldview, case study allows for the inclusion of data from both people who hoard, as well as from the professional services of people involved in these cases. Further, given that the case study allows for the inclusion of data from multiple sources, this research design is compatible with the systems theory framework used to understand the interaction of different levels of systems.

Stake (2000) asserts that with case studies “the search for particularity competes with the search for generalizability” (p. 439), stressing that the expectation in case studies is that the information from a particular case will be applicable to other cases. As such, case studies can be seen as a “typification of other cases, an exploration leading up generalization-producing studies” (Stake, 2000, p. 439). While Stake considers there to be two types of case studies, intrinsic, in which the researcher seeks a better understanding of a particular case, this research falls into the second category, instrumental. In instrumental case studies “a particular case is examined mainly to provide insight into an issue or to redraw generalization” (Stake, 2000, p. 437). The case study approach has been emphasized as more appropriate for theory building rather than

theory testing, although there is growing support for the latter as well (Berg & Lune, 2012; Woodside, 2010). Berg and Lune (2012) describe the process of developing theory from case studies as such:

Sense-making [sic] is the manner by which people, groups, and organizations make sense of stimuli with which they are confronted, how they frame what they see and hear, how they perceive and interpret this information, and how they interpret their own actions and go about solving problems and interacting with others. A case study approach to this problem-solving process can reveal both the shared and the unique sense-making decisions... (p. 328)

While this case is of interest because Waterloo Region has one of only a small number of hoarding-specific community programs available in Ontario, the intention of this research is not to examine the effectiveness of the Hoarding Project, but rather to investigate all possible determining factors that might assist people who hoard to maintain their housing. Therefore, this research falls into the instrumental category of case study research. It seeks to uncover perceptions of determining factors that may be applicable to other communities seeking to minimize the impact of evictions and loss of housing due to hoarding.

Moore, Lapan and Quartaroli (2012) emphasize the importance of bounding the case, whereby the researcher “carefully defines and clearly specifies what elements of the case will be studied” (p. 245). This case study is bounded by a geographical area, Waterloo Region. The primary focus of this case study is on people who hoard and have been potentially at risk of eviction, and includes interviews with key informants from services and enforcement agencies, and contextual data obtained through a preliminary environmental scan. Exploring the services and enforcement agencies, the contextual data from the environmental scan and the extent of hoarding of the participants allows me



gain a complete understanding of the case of Waterloo Region.

### ***3.5 Procedures***

#### ***3.5.1 Recruitment and sampling***

Participants were recruited through a network of services supporting people who hoard in Waterloo Region. Despite criticism about the potential for distortion in convenience sampling (Neuman & Kreuger, 2003), this strategy is necessary in this particular study. People who hoard are often embarrassed or ashamed of the state of their home and their hoarding behaviour. This sample represents individuals who have sought out or accepted assistance for their hoarding through their interaction with different services, which demonstrates a degree of openness about their situation. Informants who helped with recruitment contacted individuals whom they not only believed would be willing to participate in the research, but also those who are articulate in discussing their difficulties and needs. While it was not a prerequisite for participation, informants helping with recruitment also considered whether there was a discrepancy between potential participants' understanding of hoarding as problematic and socially accepted norms.

In order to be included in the study, potential participants were required to be adults, aged 18 and over, living in Waterloo Region, and who either had or were currently experiencing potential risk of eviction due to hoarding. Potential participants were also required to already have connections with services, as it was not possible to reach people who were not already involved with services. Participants did not have to have a diagnosis of HD primarily because this is a new diagnosis in the *DSM-5*, and it is unlikely

that many would have a diagnosis from a qualified mental health professional. There are a number of diagnoses to which hoarding behaviour can be attributed (Pertusa & Fonseca, 2014), however, this study focuses on problematic hoarding behaviour, therefore opening the study to participants who may hoard as a result of other diagnoses. Likewise, participants did not have to exhibit any particular degree of hoarding according to a formal assessment or measurement tool (such as the Clutter Image Rating Scale or the Hoarding Rating Scale). Due to the potential difficulty of finding participants, adding additional criteria, such as a diagnosis, or a specific level of hoarding, would have proven restrictive.

Purposive sampling was used to recruit key informants who were “particularly knowledgeable about the issues” (Engel and Schutt, 2013, p. 126). Through connections within the local community, I was able to engage social service agencies, fire safety, municipal workers, and private enterprises in my research as key informants. The primary informant<sup>2</sup> advised me as to which individuals sit on the Response to Hoarding Committee and others that have extensive experience with hoarding and would be able to provide meaningful data for the research. The primary informant was also interviewed and included as a key informant in this study. Given the size and population of Waterloo Region, it is unlikely that there are many agencies and workers in the area involved in hoarding evictions with which my primary informant has not come into contact. There are likely private enterprises, such as housing workers, professional organizers and cleaning companies with whom the primary informant may not have had contact. In addition, given the scope and timeframe of this project, it was not feasible to screen

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<sup>2</sup> The primary informant is the Hoarding Project Coordinator at Supportive Housing of Waterloo (SHOW).

housing workers in the private sector to ensure they had had extensive experience with hoarding cases, but I was able to recruit an individual in this field.

Initially I had planned to interview between four and six participants, and an additional four to six key informants. In the end, a total of six participants were interviewed, five of which lived in rental units and one lived in a privately owned home. I had initially planned exclusively to interview individuals in rental housing. However, upon commencing interviews with key informants and learning more about ways in which individuals can be at risk of losing their housing, I decided to include one individual who could speak to their experience as a home owner. I made this decision to explore differences in their experiences at being potentially at risk of losing their housing, while retaining a focus on eviction. I received a positive response from key informants selected, and a total of nine key informants were interviewed.

### *3.5.2 Data collection*

Both participant and key informant data was collected concurrently with interviews occurring between July and September 2014. All interviews were recorded using a digital audio recorder for review and transcription, as was permitted through informed consent (see Appendices D and E). The primary data source (participants) was collected from individuals who either have or are currently at risk of being evicted from their rental units, and one individual who was potentially at risk of intervention in a private home. Originally I planned to provide potential participants a letter of introduction to the study with my contact information, who could then contact me either by phone or email for more information. However, informants explained that most individuals would not be proactive in responding to a letter, and that this would be an

ineffective recruitment strategy. Individuals were thus informed of the study by phone, and gave consent to release their contact information to me for further information about the study. If the potential participants were interested, an initial meeting was set up, the official letter of introduction was given to the participant, and a time was set for the interview and formal consent.

Participant interviews were held primarily in the homes of participants, despite my presuppositions that participants may be unwilling to allow me to enter their homes. One interview was conducted in a common area of the participant's apartment building, and one interview was conducted in a classroom at Wilfrid Laurier University. Although access to the homes of these participants could provide additional insight into their living situations, I did not require that interviews be held in the homes of participants in order to protect their privacy and their preferences.

Key informant interviews were conducted with service providers, code enforcement officials, and housing workers in both the public and private sectors who engage in work with people who hoard in their professions. These included: fire prevention officers, by-law officers, private housing workers, family and children services, subsidized housing workers, the Hoarding Project, professional organizers, and supportive social service agencies. Key informants were recruited through contacts made through Waterloo Region's Response to Hoarding Network. Key informants were provided a letter of introduction to the study with the contact information of the researcher, asking interested parties to contact the researcher directly. Key informant interviews were held in the offices of each agency, in private offices or meeting spaces, the meeting room at SHOW, and one in a private home.

### *3.5.3 Data collection methods*

#### *Qualitative Interviews*

Intensive interviewing was the primary method of data collection in this study in order to discover “in-depth about people’s experiences, thoughts, and feelings on their own terms” (Engel & Schutt, 2013, p. 288). Using primarily open-ended questions, intensive interviews attempt to engage participants in dialogue about their experiences and the meanings that they assign to them (Engel & Schutt, 2013).

A total of six intensive participant interviews were conducted with people who hoard who have been or currently are potentially at risk of losing their housing. A wide range of participants was chosen due to the hidden nature of hoarding. Interviews consisted of a central grand tour question, intended to draw out “lengthy narratives” (Engel & Schutt, 2013, p. 289): what factors have helped to protect you against losing your housing when you have been/are at risk? However, additional questions that followed an interview guide were established to address key areas of interest (see Appendix F). The interview guide was developed based on my prior knowledge of hoarding from training and working as a professional organizer, as well as knowledge gained in conducting the literature review for the proposal for this study. For instance, questions regarding which public and private services participants used, and which code enforcement agencies have been involved, helped inform about the connection to these different service providers. These questions highlight gaps in service areas. Further exploratory questions provided additional insight into individuals’ perspectives and experiences. For example, these questions probed how participants reacted to service workers and code enforcement agencies, and their feelings throughout the process.

Limitations of this method may include what is referred to in mental health or psychiatric literature as a “lack of insight” on the part of the participants. There is frequently a discrepancy as to what a person who hoards considers to be problematic, and socially accepted norms of problematic levels of clutter. Initially I had concerns that this might pose challenges in participants responding to questions. However, due to the recruitment strategy, participants were generally in agreement with the socially accepted norms about the level of clutter in their homes. Prior to conducting interviews, I had intended to highlight any discrepancies regarding clutter as potentially useful in recognizing gaps in services. However, given that participants did not generally hold wildly differing views, no particular significance was assigned.

#### *Key Informant Interviews*

The nine interviews conducted with service providers or service workers provide further dimension and texture to the primary participant interviews. Although there are a greater number of key informant interviews, the primary analysis and focus is given to the participant interviews. Key informant interviews consist of a central grand tour question: in your experience, what factors have helped to protect against losing housing for individuals who hoard when they have been/are at risk? These interviews were also semi-structured, and an interview guide for each group was established to address key areas of interest (see Appendix G). The interview guide for key informants was structured to mirror that of the participants', with the intention of highlighting similar areas of inquiry (see Appendix F). Questions about the impact of working with people who hoard, and how workers felt about their work were intended to elicit responses about the difficulties

and challenges they workers might experience personally, and which may have an impact on the services they provide.

### *Environmental Scan*

A preliminary environmental scan was performed in order to paint a backdrop against which the qualitative information can be contextualized. Numerical data was collected from each of the key informants regarding the number of cases of hoarding with which they had been involved to better understand the extent that people lose their housing based on hoarding problems in Waterloo Region.

Key informants were asked to disclose the number of hoarding cases they had encountered over the time period they had been employed in that position. Given the time constraints of this project, this sample is meant to provide a rough number of hoarding cases in Waterloo Region in recent years rather than a statistically accurate representation. Most social service workers and code enforcement agencies interviewed for this study reported that few of the hoarding cases they had been involved in had resulted in eviction. While fire prevention officials in particular did report some cases had led to eviction, they did not track those statistics or have a sense of the prevalence.

However, this layered approach paints a more complex picture of the situation, from both the perspective of people who hoard, as well as workers involved in the eviction process.

### *Assessment of Hoarding in Interview Participants*

In order to determine the extent of hoarding behaviours that individual participants exhibited, I used the Clutter Image Rating Scale (CIR) (see Appendix I), designed by Frost, Steketee, Tolin and Renaud (2008). The CIR was administered to participants concurrently with the intensive interviews. The CIR is a three series of nine photographs

of the same rooms (kitchen, bedroom and living room), with an increasing amount of clutter in each room. Designed to address the issue of over- and under-reporting of hoarding, the CIR takes only a few minutes to administer, and provides a reliable method of self-assessment of the level of clutter in their homes (Frost et al., 2008). The data generated through this self-assessment was intended to gain a richer picture of the level of clutter and their living situation, particularly in instances where I did not see the participant's home. In two cases, I completed the CIR myself as the interview was conducted in the participants' homes.

#### *3.5.4 Data analysis*

Engel and Schutt (2013) state that qualitative data analysis is the focus on the text of the transcribed interviews and a way to “see the richness of real social experience” (p. 302). Further to this, “[q]ualitative data analysts seek to describe their textual data in ways that capture the setting or people who produced this text on their own terms rather than in terms of predefined measures and hypotheses” (Engel & Schutt, 2013, p. 302). Although this study is primarily qualitative in nature, the environmental scan and assessment of hoarding data are numerical in nature, and therefore are presented in chart format. The numerical data has not been analyzed independently, but rather is used to augment the qualitative data, providing context to the case study.

#### *Intensive Participant Interviews (QUAL)*

A thematic analysis (Braun & Clark, 2006) was used in interpreting the data obtained in participant interviews. Creswell (2014) describes thematic analysis as the development of themes or patterns by coding the information given by participants, which



are in turn “developed into broad patterns, theories or generalizations that are then compared with personal experiences or with existing literature on the topic” (p. 65).

Participant interviews were first transcribed from audio recordings, scrubbed for identifying information, and then read, and re-read, seeking patterns in topics of discussion. Patterns were coded using Atlas.ti (version 1.0.15 (85) for Mac), a qualitative data analysis software tool. Codes were primarily developed at the explicit or semantic level, as topics specifically discussed by the participants, although some were also developed at an interpretive level (Braun & Clarke, 2012). I created definitions for each code as I read through the transcripts and saw new codes emerging from the data. Participant data was coded in a separate Atlas.ti file from key informant data, given that while there was significant overlap in the codes found in both sets of data, there was also divergence in the data as well.

I then examined the list of over 100 codes from the participant data, determining which codes were significant based on the research question: what factors enable individuals who hoard to maintain their housing when they are potentially at risk of losing their housing? I then created a structure for the remaining codes, grouping them into thematic networks, “web-like illustrations (networks) that summarize the main themes constituting a piece of text” (Attride-Stride, 2001, p. 386). The themes found in participant interviews are what Attride-Sterling (2001) terms as ‘basic themes’, which are the “lowest order premises evident in the text” (p. 388), and are “simple premises characteristic of the data” (p. 389). The basic themes were then grouped according to ‘organizing themes’, which were both “more abstract and more revealing of what is going on in the texts” (Attride-Stirling, 2001, p. 388). Finally, the organizing themes were then

grouped together to form ‘global themes’, which “encompass the principal metaphors in the data as a whole” (Attride-Stirling, 2001, p. 389).

After creating several iterations of thematic networks, I then began writing about the identified themes. Braun and Clarke (2006) note, “[w]riting is an integral part of analysis, not something that takes place at the end, as it does with statistical analyses” (p. 86). Through the process of selecting the most salient quotes to use in the findings, I continued to revise the thematic networks, moving initially from four global themes to two. Braun and Clarke (2006) advise, “the ‘keyness’ of a theme is not necessarily dependent on quantifiable measures - but rather on whether it captures something important in relation to the overall research question” (p. 82). I used this as a guiding principle when selecting which quotes to use in the final analysis. Certain codes had a great number of quotations throughout the participant interviews, but were not necessarily of relevance to this research, nor were they telling of a particular attitude or experience. For example, all participants spoke of receiving physical help with sorting, organizing and discarding items, resulting in 64 quotations. However, this broad category provided little other insight than to confirm that participants indeed had received this type of support.

### *Key Informant Interviews*

After completing the initial reading and coding of participant data, I repeated the process with the key informant interviews using the same Atlas.ti software. Following the initial write up of findings, I then examined key informants’ data for the same (or similar) themes to those selected from the participant data. There was consistent overlap in most selected themes, and salient quotes were selected, adding dimension to the initial

analysis of participant data. Given that participant data was the focus in this research, codes found in key informant data were not organized into thematic networks. The data from key informant interviews was used as a point of comparison with the participant data, providing further dimension to the themes explored in the primary (participant) data set. Key informants also provided contextual information about the services and systems in which hoarding cases are involved. However, this information was not coded thematically, but rather highlighted throughout the interviews.

*Environmental scan* This data was collected for the purpose of providing context as to the prevalence of eviction due to hoarding in Waterloo Region. It is presented as numerical data in chart format.

*Assessment of hoarding in participants.* This data was collected for the purpose of better understanding the context of people who hoard. Again, the information collected through the CIR assessment tool helps to provide some contextual information regarding living situation of participants.

### *3.5.5 Trustworthiness of research*

The trustworthiness of qualitative research can be established through the criteria of credibility, transferability and dependability (Guba and Lincoln, 1989). In order to establish the trustworthiness of this case study, this research adheres to techniques outlined by Koch (1994).

#### *Credibility*

Koch (1994) states, “credibility is enhanced when researchers describe and interpret their experience as researchers” (p. 977). In order to increase self-awareness, I

have kept a methodological journal “in which the content and the process of interactions are noted, including reactions to various events” (Koch, 1994, p. 977).

### *Transferability*

Guba and Lincoln (1989) draw parallels between transferability and generalization, stating that with transferability “the burden of proof... is on the *receiver*” (p. 241), meaning the person conducting the research. Guba and Lincoln (1989) define transferability as “degree of similarity between two contexts” (Koch, 1994, p. 977), indicating that whether the results of the research can be transferred from one context to another will depend upon whether the contexts are sufficiently similar. Koch (1994) suggests, “the original context must be described adequately so that a judgment of transferability can be made by readers” (p. 977). Guba and Lincoln (1989, p. 241) suggest that thick descriptions are a central technique for establishing the degree of transferability. As such, I have included a section in Chapter 5, providing an in-depth description of the context of Waterloo Region. This should provide readers with sufficient information to understand whether another geographical location will be similar enough to achieve transferability.

### *Member checking*

I engaged in member checking, whereby following the completion of the analysis, some of the findings were shared with three willing participants, as well as checking quotes with six key informants. The findings were shared verbally as phone calls were the format of most meetings. I read the titles of some of the themes and provided a general description of what each theme represented. I asked for participants’ feedback as to accuracy, and participants were in general agreement with the thematic findings. The

completed version of the research will be available online through Scholars Commons repository at WLU, as well as a printed copy made available to SHOW, and any other key informants and participants who would like a copy. An executive summary of the thesis will be prepared to distribute among interested participants and key informants as well.

### *Dependability*

Koch (1994) writes that qualitative research must be demonstrated to be dependable, rather than consistent. In order to establish dependability of research, Koch suggests that an audit trail be established so that the decisions made by the researcher can be followed by another researcher. In this study I have included an audit trail “discussing explicit... decisions taken about the theoretical, methodological and analytic choices throughout the study” in my methodological journal (Koch, 1994, p. 298).

### *3.5.6 Ethical considerations*

There are a number of ethical considerations to be addressed when working with a population whose behaviour carries with it both such stigma and fascination by the general public.

### *Risks*

*Confidentiality.* For participants, the need for confidentiality is paramount. Some individuals are currently at risk of eviction, and information regarding the condition of their home or their interactions with certain agencies could compromise their housing status. Additionally, hoarding behaviours have been sensationalized and stigmatized in the mainstream media, thus participants may keep their behaviour secret from all but a few people. For both of these reasons, maintaining confidentiality with regards to the identity of participants is paramount.

Risk of identification of participants is possible as a result of the recruitment strategy. Given that participants were recruited through local agencies, it is possible that workers may know which potential participants have chosen to take part in the study. In order to maintain confidentiality, participants' contact information was disclosed to me by agency workers with explicit consent of the potential participant. This enabled me to follow up with potential participants about interviews without disclosing to agency workers as to whether the individual has chosen to participate in the research.

There is also a risk that participants could be identified by people reading the study based in information provided in direct quotations. To minimize the possibility of this occurring, transcripts were scrubbed, removing names and other identifying information. Quotes selected for the final paper had further identifying information removed, such as references to specific items that participants saved. Participants and key informants were given the option to review quotes before the final paper was published to ensure that no identifying information was released. Five of the six participants chose to review quotations, providing an additional method of minimizing the potential for identification. Similarly, participants were assigned numbers (P1, P2, etc.) rather than being given the option of choosing a pseudonym. This minimizes the potential risk that the participant could choose a pseudonym that may identify them to others.

*Psychological/Emotional Risks.* Some participants may have found that talking about their previous experiences with eviction, having to discard possessions or other difficult topics are emotionally or psychologically triggering. I asked participants how they were feeling after the interview and encouraged participants to participate in counselling if they felt distressed at any point. None of the participants reported distress at the end of the

interview, but still I provided all participants with a list of low- and no-cost counselling and crisis services in Waterloo Region, as well as the contact information for the local crisis telephone line (see Appendix H).

### *3.5.7 Benefits*

*Contribution to the literature.* Given that there is little qualitative research that focuses on the perspectives of people who hoard, and on their strengths, participants may feel a sense of pride and accomplishment in contributing to this gap in the literature.

*Potential changes to policy and services provided.* Services for people who hoard are minimal, if they exist at all, in many communities. It is possible that this research may aid in changing existing services and policies around hoarding, or may initiate new services or policies in Waterloo Region and beyond. Participants and key informants may have experienced a sense of community and connection in contributing to these developments.

*Empowerment of people who hoard.* Hoarding is sensationalized in the mainstream media, creating a culture of shame and fear around people who hoard. Additionally, much of the existing research is quantitative, and centers on developing a unique diagnosis and epidemiology of hoarding. In both of these contexts, the voices and experiences of people who hoard are lost or reduced. By engaging in this research, participants may have felt a sense of agency and empowerment in telling their own stories and knowing that these stories provide the foundation of a research project.

## CHAPTER 4

### FINDINGS

I begin this chapter by outlining the context in which this case study was conducted - Waterloo Region. This section reviews the location of Waterloo Region, the hoarding task force (called a committee in this region); the risks of eviction that people who hoard face in Waterloo Region; as well as other regulations that affect people who hoard, particularly fire code. I then present the numerical data generated in this study in three tables: the ratings of level of clutter in participants' homes using the CIR; the average rating of level of clutter in hoarding situations as reported by key informants; and the environmental scan of hoarding cases as reported by key informants. I also provide a brief overview of the implications of this data. Following this, I provide an overview of how the primary data source (participant interviews) was analyzed, and how key informant interviews were incorporated. Finally, I present the findings from this research organized thematically into two overarching themes: 1) building a relationship with people who hoard; and 2) building a framework within which to provide service.

#### ***4.1 Context of Hoarding in the Waterloo Region***

Waterloo Region is located in southern Ontario with a population of roughly 553,000 people (Region of Waterloo, n.d.). Within Waterloo Region there are three cities, commonly referred to as the “tri-city area”: Waterloo (population 98,780), Kitchener (population 219,153), and Cambridge (population 126,748) (Statistics Canada, 2012). However, Waterloo Region expands beyond the tri-city area, encompassing four rural townships: North Dumfries, Wellesley, Wilmot and Woolwich (Region of Waterloo, n.d.).



In 2008, the Waterloo Region Network: Response to Hoarding Committee was created by stakeholders who were concerned by hoarding issues in the region (“Committee aims to help hoarders”, 2011). Like many task forces or committees, the Response to Hoarding Committee did not initially receive specific funding and was comprised of stakeholders within the community who encountered hoarding behaviours in their professions. The Response to Hoarding Committee originally had a number of members who worked specifically with seniors, but later expanded to include many other services as recognition of the widespread nature of hoarding became more apparent (personal communication, K. Hodder, January 28, 2015). Chaired by Community Support Connections In-Home Services Lead Linda Flemming, the Response to Hoarding Committee received a steadily increasing number of phone calls regarding hoarding concerns: 82 in 2010, 116 in 2011 and 136 in 2012 (“Local agencies get funds to help hoarders make clean start”, 2013).

With the collaboration and support of the Response to Hoarding Committee, Supportive Housing of Waterloo (SHOW) began a three-year pilot project funded by the Ontario Trillium Foundation, called the Hoarding Project, to address hoarding needs within Waterloo Region (Waterloo Region Record, 2013). The grant enabled SHOW to hire one full time staff member to serve as the primary point of contact for both the general public and other professional stakeholders with concerns regarding hoarding. The Hoarding Project Coordinator was hired in July 2013, and under the guidance of the Response to Hoarding Committee, began to create public awareness, provide professional training, and links to services (personal communication, K. Hodder, January 28, 2015). Between September 1, 2013 and March 31, 2014 the Hoarding Project Coordinator

received 4,595 calls from the community regarding hoarding situations (K. Hodder, personal communication, April 1, 2014), demonstrating the need for support services regarding hoarding. Calls came in from a wide variety of people, including neighbours, friends, family members, service providers, landlords, property managers, and other concerned individuals (K. Hodder, personal communication, April 1, 2014). Given the overwhelming response from the community, it is clear that hoarding is an issue in need of attention in the region.

#### *4.1.1 Eviction risks for people who hoard in Waterloo Region*

As this research is qualitative in nature, an estimate of the number of evictions as a result of hoarding situations was not within the scope of this project. However, given that the literature indicates hoarding causes greater risks of eviction (Cobb et al., 2007; Landau et al., 2010; Rodriguez et al., 2012; Tolin et al., 2008), it is assumed that individuals who hoard are at potential risk of eviction. Although, significantly, one key informant, KI2, noted that in some situations tenants will leave rental units prior to being evicted rather than having to downsize the number of possessions in their apartments.

While ‘hoarding’ itself is not a reason that people can be evicted from their rental units, there are several factors that could cause a landlord to evict a tenant who hoards.

Some examples include:

- Risking the safety of other tenants. This is usually due to a high combustible load in the unit, which poses fire safety risks (Your Legal Rights, 2013);
- Willfully damaging the rental unit. This is sometimes as the result of mould or structural damage due to the volume of possessions in the unit, or not informing the

landlord of needed repairs that have resulted in further damage to the unit, e.g. leaky plumbing;

- Interfering with the reasonable enjoyment of other tenants. This could be due to odors as a result of items that have accumulated;
- Having more pets than allowed in the unit as dictated by municipal standard (Community Legal Education Ontario, 2013).

Many key informants reported that, in their experience, eviction was not common for people who hoard. For example, the one key informant recalled that out of a caseload of 109 clients, only two had been evicted, both with fairly extenuating circumstances. However, it should be noted that due to the recruitment strategy for key informants, they were likely more attuned to the legalities surrounding eviction and more aware of the needs of people who hoard, which may have been a factor in clients maintaining their housing.

#### *4.1.2 Other regulations*

During the course of interviews with both participants and key informants, it became clear that eviction was not the only risk to housing stability faced by people who hoard. In Ontario, the fire department and municipal by-law officers have significant authority. One key informant, a fire prevention official, explained that under the Ontario Fire Code the fire department has the authority to enter the home and remove accumulated items if it is deemed a severe fire risk. Similarly, the by-law official interviewed for this research explained “generally we would give a couple of weeks in order to remove the items, otherwise we would come in and do a clean up” (KI6). In these situations, the cost of removing the accumulated possessions is charged back to the

homeowner through property taxes, which is the landlord in rental properties. Although the fire prevention and by-law officials interviewed did not utilize this method to achieve compliance with clients who hoard, the threat of this consequence certainly denotes the extent of code enforcement's authority.

Involvement with fire prevention officials can signify a level of risk for eviction in rental situations, given that one of the grounds for eviction is risk to the safety of other tenants. One key informant, KI8, noted that the combustible load (ie. the amount of possessions accumulated in the home) becomes a concern starting at approximately level 5 on the Clutter Image Rating Scale. One fire prevention official explained that landlords are given notice when one of their tenants has received an order from the fire department:

[U]nder the Ontario Fire Code the owner is ultimately responsible to maintain the provisions of the fire code. So even if it's a property management company looking after that, under the Ontario Fire Code, the owner is also defined as supervisory staff. So it [the order] gets issued to the property management and the owner. (KI2)

Ultimately, in rental situations, if the tenant does not comply with an order from the fire department, the landlord can then choose to evict them. One key informant explains:

[I]t's awful to have to tell a landlord 'this is your issue too, and you need to fix it'.... [T]hey can't force them to do anything either... [T]he only option they have is to evict them and to help them. And a lot of them do [help tenants who hoard]... They will rent dumpsters... [but] ultimately their only choice is to evict them... (KI8)

This key informant indicates that landlords have a level of responsibility to help tenants who hoard to comply with the fire code. However, ultimately, the only recourse landlords have when tenants are not able to comply is to evict them.

Homeowners have marginally more control over their housing situations, given that they can not be evicted from a home that they own. Homeowners can be forced out

of their home if the building is condemned due to structural damage. A key informant explains that this is not a common occurrence:

I've maybe worked with about two or three, homes that have been at risk of being condemned. And those were because the electricity wasn't working, there were no working toilets in the house... a lot of bio-hazardous, like, body waste in buckets around the home. This one home in [name of town]... the back half of her house was actually sagging, and falling... (KI1)

While it is unusual for a home to be condemned, there are safety considerations that sometimes make this a reality.

Individuals who live in condominiums, while they are technically homeowners, have to adhere to rules put in place by the condominium corporation. One key informant explains:

[C]ondominium corporations have rules and regulations and by-laws and declarations for which the owners, who are shareholders in the corporation, have to follow. So, we can rely on those in order to have them comply with any issues that surround the hoarding that we have found. (KI3)

She goes on to explain that the condominium corporation can charge the condo unit owner for any expenses incurred. She describes the financial and legal consequences this can have: "[I]f they don't pay them, within ninety days, we can actually put a lean against their unit, which affect[s] the sale of their unit" (KI3). The issue of ownership and responsibility is complicated in condominiums. One key informant explains:

With a condo corporation, every owner is a shareholder in the entire common areas, and those are specifically listed in what we call a standard unit description, so, while the owner owns the interior of their unit, usually, the walls, the windows, the roofs, et cetera are owned by the condo corporation, so if they're doing something that's causing damage, hoarding having you know, window rot et cetera... [then] the corporation has to pay for those to be repaired... (KI3)

While the individual owns the unit, the condominium corporation still has a responsibility for repairs and maintenance of certain parts of the building, not dissimilar to a rental unit. Not only could people who hoard be under financial and legal pressure from the condominium corporation, but neighbours and other unit owners in the building may apply pressure to the property management company or board of directors to address any issues that could be caused by hoarding.

Table 1 outlines the volume of clutter in the homes of participants. There are many different factors that can contribute to the potential risk of eviction, as outlined in the above section. These numbers simply provide a general sense of the living situation of the participants in this research.

#### ***4.2 Level of Clutter Data and Preliminary Environmental Scan Data***

This section presents, in table format, the numerical data indicating the level of clutter in each of the participants' homes and the general level of clutter as seen in hoarding situations by the key informants interviewed for this research. The data collected for the preliminary environmental scan is also presented, giving a cursory understanding as to the number of hoarding cases encountered by workers in different fields.

*Table 1. Ratings of Level of Clutter in Participants' Homes Using CIR*

Participant	Kitchen	Bedroom	Living Room	Overall
P1*	4-5	4-5	6	5
P2**	N/A	N/A	N/A	1
P3*	6-7	N/A	6-7	6-7
P4	N/A	9	2-4	4*
P5	2 currently 3-4 before support	3 currently 3 before support	3 currently 6 before support	
P6	1-2	1-2	1-2	Basement: 6-7

\* My assessment based on areas of the home that I saw during the interview.

\*\*P2 felt that none of the images on the CIR scale represented how her apartment looked prior to intervention, given that her belongings were neatly organized and stacked.

*Table 2. Average Rating of Level of Clutter in Hoarding Situations as Reported by Key Informants*

Key Informant	Kitchen	Bedroom	Living Room	Overall
KI1 Support Services	3-4		3-4	5-6
KI2 Fire Prevention				5-6
KI3 Housing Worker	4-6	7	6-7	5-6
KI4 Subsidized Housing				3-4
KI5 Family Children's Services				7-8
KI6 By-Law				5
KI7 Professional Organizer				7
KI8 Fire Prevention	3-9 (usually 8-9)	2-9 (usually 7-9)	2-9 (mostly 7-9)	7-9
KI9 Support Services				6-8

As indicated in the tables above, both participants and key informants indicated that the level of clutter in homes that were considered to have hoarding problems were generally rated as 5 and above on the Clutter Image Rating Scale. While participants did not necessarily describe the level of clutter in their homes as being problematic, their

involvement with services and code enforcement indicates that an assessment of the level of clutter as being problematic was made by at least one worker.

In their interviews, some key informants distinguished between what professional organizers refer to as ‘situational disorganization’ and ‘chronic or habitual disorganization’ (Price, 2012). Situational disorganization refers to clutter resulting from a life event such as the death of a loved one, inheriting possessions from someone, a divorce, or other life-changing event that can cause temporary disorganization and accumulation of possessions. This is distinct from chronic or habitual disorganization, where individuals have long-term problems with sorting, organizing or discarding possessions, sometimes as a result of hoarding or other problems. However, not all key informants are involved in hoarding situations to the extent that they might be able to make this assessment. For example, code enforcement officials may not be aware of whether the accumulated items have been a long or short-term problem. As such, these numbers assume that the situations that key informants were involved in were, in fact, hoarding situations rather than temporary, situational disorganized circumstances.



*Table 3. Environmental Scan of Hoarding Cases as Reported by Key Informants*

Key Informant	Number of Years in Position	Number of Hoarding Situations Involved In	Average Number of Hoarding Situation Per Year
KI1 Support Services	4	50 - 100	
KI2 Fire Prevention	8		8-10 annually
KI3 Housing Worker	5	3	All three in one year
KI4 Subsidized Housing	10	25	2 per year (approx.)
KI5 Family Children's Services	12-13	12-15	1-2 on caseload at any given time
KI6 By-Law	21	5-6	5-6
KI7 Professional Organizer	10	10-15	
KI8 Fire Prevention	4.5	80	
KI9 Support Services	1.5	109	

The number of hoarding cases encountered by key informants in a range of professions in the community help to give a sense of the frequency with which people in these professions generally come across hoarding situations. Certain professions may be more likely to encounter hoarding situations, such as fire prevention officials, who report seeing between 10 and 20 cases of hoarding per year. Given that fire prevention officials are often involved in identifying hoarding situations, but are not involved in a supportive capacity, the need for training about hoarding and links to supportive services could be important. However, other supportive and social services indicated seeing a high number of cases (between 12 and 25 for KI1), indicating that certain supportive services are called in frequently in hoarding cases, and may bear the brunt of the time and resources allocated in these situations.

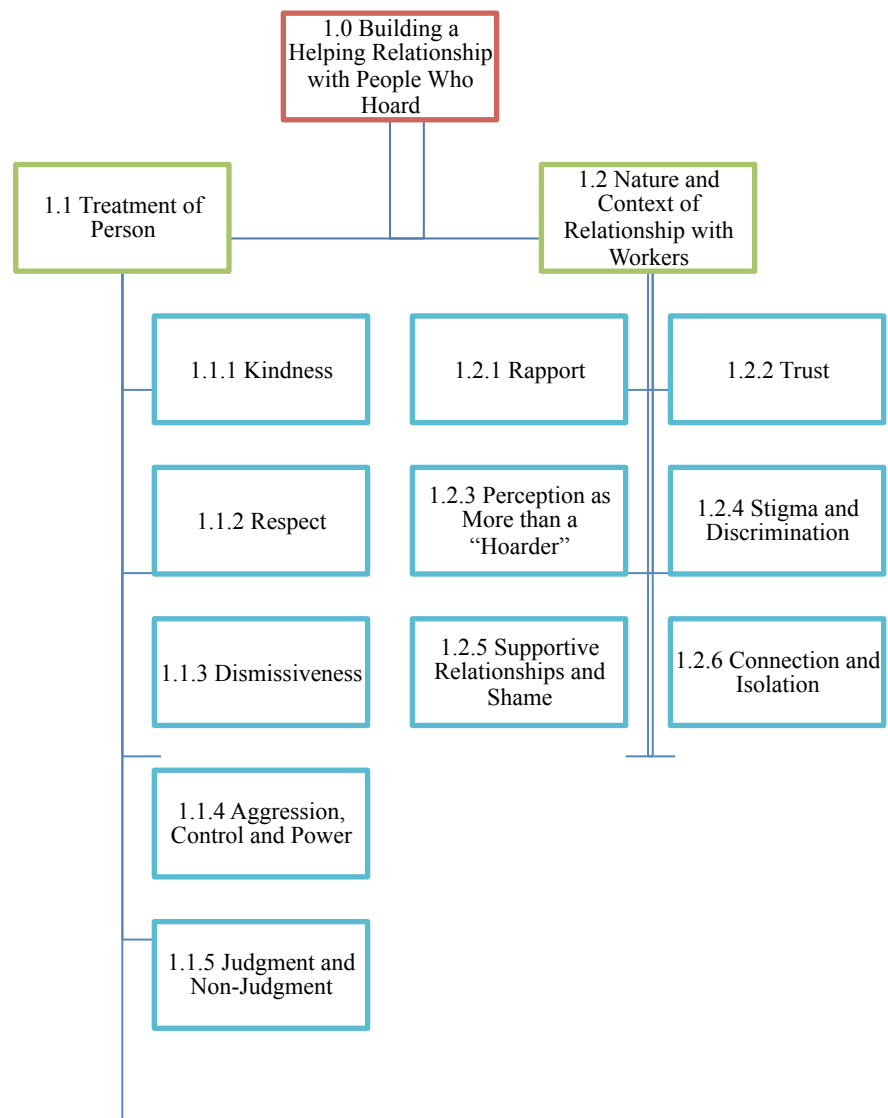
### ***4.3 Study Findings***

Participant interviews were analyzed thematically, seeking patterns and commonalities about which the individuals spoke. Key informants' interviews were then reviewed for themes separately. While there was significant overlap in the themes from both participants and key informants, the presence of the theme in both sets of data was not a prerequisite for inclusion in the findings. Prevalence was given to data from the participants, and it was then compared and contrasted with overlapping themes in the key informant data. The themes were organized according to what Attride-Stirling (2001) refers to as thematic networks. As described in the data analysis section, themes were grouped into three levels of categorization: basic, representing the data; organizing, which are more abstract; and then global themes that "encompass the principle metaphors in the data as a whole" (Attride-Sterling, 2001, p. 389). Ultimately, I identified two global themes: 1) Building a Helping Relationship with People Who Hoard; and 2) Building a Framework within which to Provide Service. The organizing and basic themes are outlined in the following sections, with direct quotations from both participants and key informants.

One of the participants was male and most (n=5) were renters. In the interest of protecting the identity of participants in this case study, I did not collect extensive demographic information about participants, as risk of confidentiality will preclude the inclusion of this information.

### ***1. Global Theme #1: Building a Helping Relationship with People Who Hoard***

This theme grew out of recognizing the myriad ways in which participants identified relationships as both helpful and detrimental in the process of maintaining their housing. However, the central theme was to develop a positive relationship between participants and other people in their lives.



*Graph 1. Thematic Network 1.0: Building a Helping Relationship with People Who Hoard*

### ***1.1 Organizing Theme: Treatment of Person***

Participants spoke at length about ways in which they had been treated by social service workers, code enforcement officials, family members, housing workers, and many others in their lives', and how this related to the process of maintaining their homes.

#### ***1.1.1 Kindness***

It would seem obvious that kindness and compassion would be central to developing a helping relationship with anyone. However, one participant was surprised that a worker was kind to her, "he kept astonishing me. By being nice" (P4). A second participant spoke of her appreciation that a worker would treat her compassionately:

[He] called me to his smaller office [and] he said 'do you want some privacy to talk with me'. So I [emphasis] absolutely appreciated that he did that. I don't like standing there, and you've got people at the counter, people at the waiting area... they're all overhearing me have a concern and, and I hate feeling so conspicuous. (P6)

Often clients of social services enter public offices, such as employment, housing, or counselling services, and are expected to have deeply personal, and oftentimes painful conversations with a person in authority, with every other client in the waiting room privy to that conversation. This participant interpreted the privacy afforded to her by a worker as an act of kindness, given that it was outside the norm in the context of that professional relationship, and therefore helpful in developing a supportive relationship.

#### ***1.1.2 Respect***

Respect played a central role in developing a helping relationship with participants, especially by individuals working for social services and other people in positions of authority. One participant states:

We already probably [have] issues, maybe employment struggles, mental health issues, whatever else... and so at the very least be as respectful to us

as you would anybody else in your life or in your day and in some sense even more so because we come with a different set of issues or concerns or struggles... (P6)

This participant identifies the vulnerability of people who hoard, who are accessing services for a variety of reasons. Given the stigma that hoarding carries with it, and the shame that many people who hoard feel about this behaviour, she identifies that treating the individual with respect will further the relationship.

Respect, for one participant, meant being treated with personal agency.

Considering the intrusion of code enforcement officials and social services workers into hoarding situations, participants wanted to be treated respectfully by those workers. Being involved in the process is vital, and one participant was critical when various services communicated with each other without keeping her, as a client, informed as to the next steps. She reports: “[I]t really bothered me that he didn’t phone me too... Well, I found it kind of demeaning, kind of like, ‘what am I, chopped liver?’ you know?” (P3). She alludes to her feelings of powerlessness within the process, but also the disrespect on the part of the workers involved. Key informants reiterated the importance of treating the client with respect with regards to their involvement in the process:

I would work along side her because the thing is [pauses] it’s their stuff, so you can’t just go in there and start taking it all you always have to work with them and say ‘what do you want to keep and what do you not’ and negotiate... (KI1)

I always try to be very respectful of the fact that a) it’s somebody’s property, secondly, I mean, it’s their feelings and you always have to treat everybody with respect, regardless if you agree with how they live or not. (KI6)

One participant was explicit in her gratitude to service workers when she was treated with respect: “he has been so professional and I really truly appreciate the way he has treated

me” (P1).

Participants identified that a lack of respect was detrimental to developing a relationship, and in some cases, even worsened the situation. One participant explained: “[a local lawyer] was so horrible to me. [Emphasis] Wildly inappropriate. I didn’t get any help there. Just a little bit of mediation there would have really helped the situation” (P4), indicating that even in the context of seeking legal council, she was not respected, which ultimately created larger problems.

### *1.1.3 Dismissiveness*

Participants spoke about workers dismissing them in different ways, highlighting the importance of workers recognizing that hoarding is not an easily solved issue, and one that requires support from many different personal and professional avenues. One participant recalls:

I had taken pictures in to my family doctor. [Pauses] I mean obviously bad pictures. [Pauses] I don’t know why I took them in. I think it was a plea for help. But she didn’t follow up... She said ‘well you’re going to have to get after that. Just do it’. [Frustrated] If I could do it then I would [emphasis] do it. (P1)

As discussed in chapter 2, services specifically for people who hoard are almost non-existent in Canada, with a few fledging programs like the Hoarding Project. Dismissal of the problem by a worker only further serves to stigmatize hoarding as simple laziness on the part of the client.

Participants’ need and desire to be involved in the process of maintaining their home is undermined by workers’ dismissive attitudes. Participants explain that workers tended to focus on the possessions and the physical environment, rather than on them, as the owner of those possessions. A participant explains: “I would tell the story if they

were interested...I mean these people are not interested in what I have to say about this particular item” (P5). In this case, the worker minimizes the concerns of the participant, with a single-minded focus on the job at hand, forgetting that it is not simply a matter of downsizing possessions that needs to be addressed, but an emotional and psychological interaction with a human being.

#### *1.1.4 Aggression, control and power*

Participants experienced workers as overly aggressive in the ways they interacted with them, attempting to control participants and force them to conform to standards of “normal” behaviour:

I started to say something else about wanting to really understand why I’ve got different messages [about the process] and she said ‘I don’t want to argue with you. You need to leave’ and I’m trying to say ‘I don’t want to argue either but this is my life. Like, this is my home’...(P6)

Despite the potentially dire consequences of losing her home, the worker in this situation had made a decision and was unwilling to listen to the participant. Controlling the behaviour of people who hoard underscores the larger issue of the power differential in these relationships, where, ultimately, participants felt as though they had no choice but to submit to the demands of the workers involved in their case:

Well I always went along with it. Whatever was suggested, I would always do it because well maybe it will be helpful or I would just go along with it just so that I wasn’t listed as non-compliant. Because you can be listed as non-compliant and that’s not a good list to be on as far as I can see [laughs]...So I always tried to stay in the white book as opposed to the black book [laughs]. (P5)

The consequences of non-compliance in hoarding cases can result in the individual losing their housing or their possessions. While this participant intones reluctance to comply with the demands of the worker involved, he does not feel as though he has a choice in

the matter.

Further highlighting the power differential between workers and participants, in some cases participants felt coerced into compliance by those with whom they worked. One participant states: “No I don't really have a choice... If I don't comply to that, then she's gonna do another route” (P5), indicating that regardless of what he agrees to, the worker will find another way of achieving their goal. Another participant identifies the consequences of not complying with the agencies involved in her case:

I did get an eviction notice. When I refused to let them in for an inspection. Because I knew what they were wanting to do. They were just wanting to look around and go ‘this is wrong, this is wrong, this is wrong, this is wrong, you’d better fix it or else’. And it was a power struggle. (P4)

This participant highlights the discrepancy between the worker’s intention and how the participant perceived the worker’s actions. While others involved may feel that they are doing a service to someone who hoards by attempting to change their behaviour, or remove items from their home, this participant interpreted these actions as social control. Meanwhile, one participant perceives an aggressive worker as more than just an agent of social control: “For me, it’s like abuse all over again. It’s somebody is just [emphasis] yelling and has that power over me” (P6), likening this relationship to an abusive one.

Despite the power differential between participants and workers, one participant was empathetic to workers, finding reasons for the forceful behaviour: “well I guess probably what I figured out with her was [why] she was so mean. Cause she isn’t ordinarily, she’s quite friendly. But I think she was afraid for her own job.” (P2). This participant highlights the fear associated with hoarding. The stigma associated with hoarding as dirty and unkempt, as well as the confusion about the legalities surrounding hoarding can cause workers involved with cases of hoarding to react in not only an



unprofessional manner, but also beyond the limits of their authority.

While participants found individuals involved in their case to be aggressive and controlling in many situations, key informants were aware of the negative impact of this tactic:

Like if I come in there very forceful and say you need to do this now, you need to get this done and if my attitude is like that, that's going to just put up their guard, and they're not going to want me in their house, they're going to kick me out, tell me to get out, or they won't let me in. (K12)

This worker acknowledges the importance of not being aggressive in his interactions with clients who hoard in order to work towards compliance.

#### *1.1.5 Judgment and non-judgment*

All participants spoke about experiences of being judged about their hoarding with both workers and non-workers. The underlying narrative throughout these comments is a desire not to be judged as lacking or deficient by others. One participant outlined this explicitly:

[J]ust like 'you can't do it, you're not as capable as I am'. Maybe 'I'm more capable than you are'. Um, and 'I'm certainly more organized than you are' you know like that would be in her head. She didn't [emphasis] say that but you know... (P3)

She exposes how she read the behaviour of this person towards her, rather than the verbalized opinions of this individual.

Another participant addressed the evaluation of her home by workers: "Apparently I was living in a squalid death trap and I needed to be saved from myself and they were gonna go to the tribunal if necessary" (P4). This comment highlights the discrepancy between her experience and that of the workers involved. While the worker may have been focusing on fire, health and safety concerns, the participant read that as

harsh judgment about how she chooses to live her life.

The same participant made a link between being judged by others, and the inclination to simply follow the dominant discourse about one's self as a "hoarder". One participant states:

[H]ere's the thing is that if the hoarder's already feeling overwhelmed, guilty, a perfectionist, I'm not doing it right... and someone comes in and goes 'this is [emphasis] terrible, this is disgusting' comes in with judgment...you're gonna feel even more [sic], and then the landlord who says 'you do this or you're gonna be evicted' well. There's a certain amount of logic that goes on saying 'well, I'm not doing this right. Maybe he can evict me for it'. (P4)

She highlights the effect that judgments from workers can have on a person who hoards, explaining that the institutional power workers carry with them can cause the individual to question the choices that they have made. As explored in depth later, lack of knowledge about rights and the limits of authority of workers (both by the people who hoard and workers themselves) can have negative consequences, whereby individuals are subjected to greater social controls that is actually within the power of the worker to enact.

Key informants, again, echoed the need for non-judgment when working with clients who hoard. One key informant states: "as long as she feels that her back doesn't go up and she's not feeling judged, then she's fine but if you hit the wrong spot with her, she could be a little fireball" (KI5) clearly outlining that judgment puts a halt to any progress. Similarly, another key informant identifies the need for non-judgment in developing rapport with a client:

You also have to let them know that you're not there to judge what their circumstances are, or judge their cleanliness, or the clutter in their home. You're just there to ensure that they are safe. And that usually works. That usually helps to create a rapport with the client and you can usually move forward then. (KI2)

Ultimately, a non-judgmental attitude from the workers involved is helpful in ensuring that people who hoard maintain their homes.

### ***1.2 Organizing Theme: Nature and Context of Relationship with Workers***

Participants spoke at length about the nature and context of their relationship with the various workers involved in their cases. Given the breadth of types of workers involved in hoarding cases, the context of the relationship influenced the interactions with participants both negatively and positively. However, the context of the relationship was not the only factor influencing these relationships; the nature of the relationship was textured and varied beyond simple divisions based on professional designation.

#### ***1.2.1 Rapport***

Rapport building was an essential component across client-worker relationships. One participant explains the difficulty in developing new relationships:

I got up enough nerve to call, you have to understand I really have to work up to call somebody. Like you [referring to interviewer] are a known entity now and I feel free to speak with you but that initial encounter is difficult.  
(P1)

The stigma associated with hoarding can prevent individuals from disclosing the issue to others. As another participant reported “you don’t just pick anybody to share this and disclose because you may not find [laughing] find somebody that’s understanding. It has to be a careful decision” (P6). The workers response to the initial disclosure of hoarding is a key component in establishing rapport with the individual.

A sense of genuine engagement on the part of the worker can also be important. One participant reports: “just, the interest you know. That somebody cares. To see that it’s being done” (P2) was helpful in her case. Meanwhile, another participant identifies

that for her, workers involvement “had nothing to do with what was in my best interests, which they claimed. ‘We’re just concerned about you’. No, you’re being controlling” (P4). However, this participant identifies the nuanced but significant difference in the tone of the relationship by focusing on her “best interests”. She implies that the relationship was paternalistic in nature, and therefore could not be a genuine, caring relationship. One key informant reinforces the need for a genuinely authentic caring relationship with clients:

[R]eally handing [the power] over to [emphasis] them, but being there to support them while they make those decisions and helping them pull in the right people that can support them on their journey and their path. I think you see kind of a light bulb go off, like, ‘okay this is somebody that actually [pauses] wants the best for me and isn’t here because it’s just their job or it’s just something that they do every day’... (KI9)

One participant identified the importance of the ongoing relationship with a particular worker:

[H]aving somebody like [name of worker] to work with...I felt very comfortable to have her around. Even if she wasn’t doing too much of the physical stuff, that’s mostly me, that’s okay because she was supplying some much needed psychological support. (P3)

In this case, the rapport developed between the worker and the participant enabled the participant to make progress with the physical aspect of her hoarding problem.

Ultimately, the goal in most situations where code enforcement and housing workers are involved is to minimize the physical impacts of the hoarding problem, rather than addressing the psychological aspects. This participant links the benefits of rapport with the physical work of organizing and discarding items, and ultimately maintaining her home.

Key informants spoke at length about developing rapport with clients who hoard:

I try to talk to people how I would want to be talked to, and I try to sit down with people and really work out a plan that works for them, and I try to make it about them. ‘Cause ideally, it [emphasis] is about them, it’s about what they need and what’s going on in their home, and in their space. So I just try to word it from that point of view[.] (KI9)

I have a very good rapport with the people. I’ve had one scenario where a woman was standing on her porch yelling at me, telling me that you’re not coming in and by the time we were finished, we had conversations, about...her family and her cat. (KI2)

Well and I think it helps, I’ve only known [name of client] for about a year, but I’ve known [name of another client] for about three or four years now, and now they’ve both been quite receptive to the support offered, but I think that’s because where there’s a relationship there, I think if I was an intake worker... it would be seen as like a means to an end or...’cause we get a lot people who just think that we’re just there to take the kids. (KI5)

Their statements reinforce the need to develop a genuine rapport with clients in order to work effectively together.

### *1.2.2 Trust*

Another key element in the relationship that emerged between workers and participants is trust. Trust is linked closely with the importance of having control over the process and possessions (discussed in depth later in this chapter). One participant explains: “just maybe my own attitude that I don’t trust people more to help, that I do feel the need to have some more control over the situation. That hasn’t been particularly helpful” (P3). She acknowledges that progress in terms of adhering to the physical regulations would be easier to achieve with help from others, but a lack of trust prevents her from allowing others to control or be more involved in that process.

Participants indicated their uneasiness with workers whom they did not trust. A participant explained “[t]he helper stayed and was working with me and then this other

guy he was always in the back... I didn't really feel comfortable that he was involved”

(P5). Another participant denied support from one agency as a result of lack of trust with a particular worker:

[The services were] offered. And honestly I was leery of [the agency]... I just didn't feel good about [the worker]. [I] felt from the very beginning like she was going to tell me what to get rid of and [in] fact she even took [an item.] (P2)

This participant highlights the damage to the relationship when individuals remove items from the home without the knowledge or against the wishes of an individual who hoards. Tompkins & Hartl (2009) refer to this as a common problem in families, where out of frustration family members remove items from the homes of their loved one who hoards, breaking trust and damaging a helpful, productive relationship.

Another participant links trust with a supportive relationship, where the worker offers more than judgment:

I'm like no, I'm not wasting [emphasis] any energy [emphasis] learning to trust another person who's going to do nothing but tell me that [emphasis] everything I'm doing is completely wrong. I'm not investing that energy in anybody for that if that's what the outcome is going to be. (P4)

She infers that in trusting a new worker, there is a process of developing a rapport and of then disclosing, a process that she refuses to engage in if the worker is overly judgmental.

A code enforcement official outlined the need for trust: “Once they figure out that they can trust you, you're not going to close them down or kick them out, and that you're not there to judge. I think that's important” (KI2). Given the power differential, particularly in relationships between code enforcement and clients who hoard, trust becomes a vital part of the working relationship.

### *1.2.3 Perception as more than a “hoarder”*

Participants spoke about others perceiving them as more than simply a person who hoards. One participant explains, “it does your ego good to know that they know you’re a fun person underneath all of this other stuff” (P1). Meanwhile, another participant equates treatment of herself with the way others treat her possessions:

So why would I want that to go in the garbage? Like it just devalues you even more...you know what I mean? Devalues me even more? ...It makes [emphasis] me feel even more like trash. (P3)

Frost and Steketee (2010) write that, “Hoarded objects become part of the hoarder’s identity or personal history. In a sense, they come to define his or her identity” (p. 101). These words suggest it is important for the person who hoards to be recognized as having an identity as full as the breadth and depth as their possessions. Participants spoke about some of their possessions in a manner that exemplified their rich and full lives, depicting themselves as more than simply a “hoarder”. One participant recounted: “my [family has] come to the realization that I’ve actually read all of these books” (P1), expressing the importance that her loved ones understand that her books are part of who she is, and she is more than just a person who hoards. Another participant expressed her distress at the thought of having to give up a part of herself in the process of downsizing her possessions:

...I was so worked up saying ‘...I can’t fit [emphasis] my stuff, I can’t have my [family] with me... I can’t not have my [family’s] [emphasis] stuff with me, even if my [family isn’t] with me’. (P6)

She exposes the complex relationship with her and her family’s possessions: on one hand, she is a whole and complete person, not simply the stigmatized label of “hoarder”; on the other hand, her identity is bound up as a family woman, making it difficult to part with

the possessions that help to define her as such. While not explicitly identified by participants, it is clear that understanding their value as whole and complete beings, and the connection to their possessions is significant in developing a meaningful relationship.

One key informant expressed understanding of the complexity of hoarding:

[T]here's lots of mean things that people say. And they're struggling individuals and nine times out of ten they had some sort of crisis in their life that lead them to this point, and I feel sorry for them, I really do. Like I think, you know, there's some people that can be fairly cold toward that, but the more I work with them, the more I realize that it's pretty complicated. (KI7)

She implies a similar discourse of seeing people who hoard as more than just the sum of their problems, understanding that while hoarding is an aspect of their lives and their personalities, it is a result of complex situations rather than a defining feature of their character.

#### *1.2.4 Stigma and discrimination*

Participants spoke about the social stigma attached to mental health problems, hoarding specifically, as well as the discrimination they faced as a result of that stigma.

"I say crazy is the new Black [laughs]. Used to be you had to be Black to get this kind of discrimination, turns out all you have to be is crazy" (P4) says one participant, clearly linking discrimination with mental health. Another participant explains, "I think I was tainted by watching *Hoarders* on TV... Because I said "they're all fat and stupid" [laughs]... at least they portray them as [emphasis] idiots at time[s]" (P1) referring to the sensationalist A&E reality TV show that aired for six seasons between 2009 and 2013.



One participant speaks about her experience:

Why is [housing agency] perpetuating [a] [emphasis] hideous stereotype like that? That, if I'm a mental patient, it automatically means that I'm doing something stupid, crazy dangerous, like lighting fires? That was a horrible, horrible stereotype for them to say to her, and for her to repeat. (P4)

She links the common perception that people with mental health diagnoses are dangerous by nature, with the need to be controlled for the safety of the general public. This is a perception that applies to hoarding problems through fears about pest infestation, damage to property (mould, etc.) and perhaps most of all, fire hazards due to the accumulation of possessions. She continues:

I think there's discrimination when you're a hoarder if people just think you're unclean, untidy, worthy to be laughed at. You know if [you]... live in a clean, orderly home and all your friends have clean, orderly homes and everyone you know has clean, orderly homes and you feel maybe a little superior about that and you feel judgmental [towards] someone who's not able to keep up to that standard...which is... totally not helpful with a hoarder, to do that. (P4)

A participant explains that workers he has encountered have been quick to label him with mental health conditions: "...they would accuse you of different you know [referring to diagnoses] or they would diagnose you with [laughs] certain things and I'm thinking well I think I've proved to myself that whatever they're saying is not necessarily right" (P5). He exposes the discrepancy between his perceptions of his mental health and the workers with whom he interacts. He goes on to explain that these diagnostic labels feel like accusations: "I always feel as though [pauses] people, like I've never been [emphasis] diagnosed for [chuckling] anything but people are [laughing] accusing me..." perhaps referring to workers making assumptions about his mental health status without having a diagnosis. This speaks to a larger problem within human service and para-

medical professions, where workers refer to clients as having mental health diagnoses without having an actual, official diagnosis from a professional qualified to make such an assessment.

Discrimination due to hoarding can be used as a way to limit the accountability of the landlord in rental situations:

[A] previous landlord that I had, it was [an] apartment that got flooded and when I asked for repairs that was one of the things he threw back in my face ‘well you have too much stuff in your house, that’s the real problem’.  
(P4)

Rather than addressing the flood damage, this landlord attempts to shift blame onto this participant by addressing the accumulation of possessions.

Meanwhile, one code enforcement official identified the positive role that she has seen as a result of the TV show *Hoarders*:

I think people didn’t understand what hoarding was, and when they actually watch that show and see how stressed people are when there’s somebody in there trying to take their stuff, and just how bad people can hoard, and the different reasons that they do it. I think it’s bought us a little bit of patience with [people reporting hoarding]... if nothing else that has kind of opened people’s eyes to, this is a real issue, it’s not just somebody who’s lazy and doesn’t want to get rid of their stuff. (KI6)

While this key informant’s perspective contrasts with the experience of the participant who spoke about the TV show, she highlights the need for public awareness and education around the issue of hoarding, particularly in de-stigmatizing people who hoard.

#### *1.2.5 Supportive relationships and shame*

Participants spoke about different types of supportive relationships as being helpful in maintaining their homes. Characterizations of ‘supportive’ differed between participants, revolving around notions of shame, empathy, and non-judgment.

Mental health has such a stigma to it. And I know this probably [emphasis]

sounds crazy, but talking about it helps. I think acknowledging it and talking about it and trying to get beyond the shame and realizing that it's just another part of your body that can get sick. (P1)

This participant experiences support as being able to discuss mental health and shame.

Similarly, another participant states:

Just to let people know. Because the longer you [emphasis] hide or keep it, the more you build it up to be such a big awful [emphasis] thing, like it's a character flaw or something... Because there's a value in [emphasis] being vulnerable, saying 'I don't do well, this is something I can't cope with. Can I let you in and can you help me? Can you see this and help me deal with it?'. So just to encourage people to not hide it, to not [emphasis] deny it, not put it off, so really face it. (P6)

She echoes the importance of disclosing to others the struggle of hoarding, exposing the need to de-mystify the problem, and not afford it greater power. Meanwhile, another participant explores the power of empathy:

I have been in other people's homes now since my own, and have seen their stuff and I'm appalled 'cause I would say "oh my gosh you look so professional and I had no idea that this is what you come home to at the end of every day" so just in me recognizing, it's a humbling experience, recognizing that people do have things that they hide. (P6)

In seeing that, despite appearances, others struggle with similar problems, she can empathize with the shame that other people feel.

#### *1.2.6 Connection and isolation*

Participants spoke about the importance of connection, both individual and community. One participant described her religious affiliation:

I thought 'yeah, this feels comfortable. I think I'm gonna continue [a second religion] even though I retain being [first religion]'. I enjoy the people, I enjoy what's going on, and it's the social contact that I need. And especially cause I'm an intellectual and so I don't mix in a lot of places. (P2)

For her, having this connection to the community and to others is important, providing a

sense of belonging. Similarly, another participant describes:

I ended up doing a fair bit of research... tracking down places that gave things away. ...[I]t very much slowed the process down, but it benefitted me in realizing what outreach we do have at various agencies or churches in our community so that was knowledge for me that I didn't have previously. And [emphasis] really good conversations and contact with these people. (P6)

For her, education about what services were available helped to develop a sense of connection and belonging to the larger community, and was a significant part of the process of discarding possessions.

On an individual level, one participant reported: "I used to just phone somebody and I wouldn't say that I was depressed or anything. I would just have a conversation and that sort of took the edge off of whatever I was feeling" (P5), expressing the same need for connection as the previous participants. Similarly, another participant describes her relationship with a mental health professional:

I think loneliness is a major thing for me. Just somebody to talk to who's non-judgmental. Which is where [name of worker] comes in but I can't phone her up every day. We have done breakfast. [laughs] I mean she's very approachable and that's certainly the kind of mental health worker you need. Someone who [pauses] has boundaries but still doesn't push you away. (P1)

While she recognizes the limits of a professional relationship, she specifies the importance of the social nature of the relationship. Likewise, another participant reports "when I spend time with kids. [That] [g]ives me energy and gets me motivated. That's, huge for me" (P4). Participants indicated a wide variety of places where they connected to people individually and on a community level. However, the sense of belonging and human connection was consistent throughout the interviews as important.

One key informant indicated that connection is often lacking for clients who

hoard:

[A] lot of the people that I work with, when they come to me they're quite insecure about their hoarding, they don't really want to talk to too many people about it, they don't want to let too many new people [emphasis] in. [It is a] very big step for them to let someone into their home. A lot of my clients haven't had people into their home for 10 to 20 or 30 years... so the fact that they're letting me come and sit in their living room with them is a [emphasis] huge accomplishment. That's a huge success in itself. (KI9)

She identifies making steps towards social contact as important for many hoarding clients.

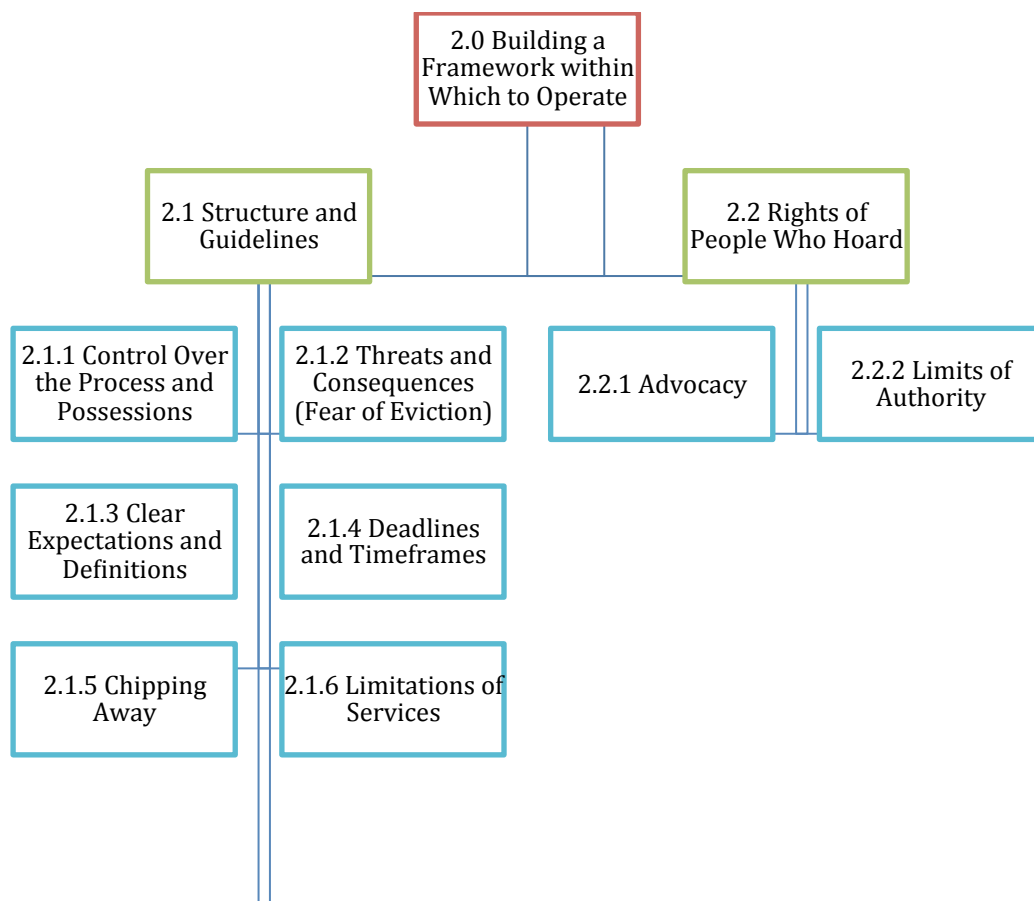
Similarly, key informants reported that many clients who hoard are isolated from their families: "I've had a couple of cases where family have really stepped up and helped. But unfortunately, a lot of these folks are very... isolated from their families" (KI1).

However, another key informant identifies that when families are involved in the process, that they can help with progress:

I think a lot of the hoarders I've dealt with are on their own, living on their own. Isolated. ...[A] lot of their families don't know they are [hoarding], so once they are aware of what's going on and... are there to help the person, I find that that helps a lot. (KI8)

## ***2. Global Theme #2: Building a Framework within which to Provide Service***

Participants spoke about the framework within which professional interactions with people who hoard occurred. Understanding how people who hoard interact with the social systems that are imposed on them helps to determine what aspects of this framework are helpful, and what aspect cause further hindrance in maintaining their housing.



*Graph 2. Thematic Network 2: Building a Framework within which to Provide Service*

## ***2.1 Organizing Theme: Structure and Guidelines***

Participants spoke about a multitude of ways in which service providers, code enforcement officials, and housing workers created guidelines and structures within which to operate. While some of these strategies were helpful in motivating participants, others served to de-motivate and in some cases caused an almost total paralysis in terms of progress towards goals. This theme refers to the involvement of client-worker relationships, as opposed to family, friends and other community relationships, although the findings in some themes may be relevant in informal relationships as well.

### ***2.1.1 Control over the process and possessions***

In a study about the role of beliefs and attitudes in the maintenance and possibly etiology of hoarding using a new self-report instrument, Steketee, Frost, and Kyrios (2003) identified a strong association between beliefs about control over possessions and hoarding behaviours. This was echoed in the statements that participants made in this research. One participant states, “ I don’t know what [name of professional organizer]’s like so I don’t know how it would be working with her. I am kind of a little bit scared to give up all the control” (P3). She indicates her hesitancy in having an unknown person involved in the process of sorting and discarding her possessions. This participant describes the style of physical help she would like to have: “somebody who could come in the way movers come in and they you know, ‘okay you can take that, you can take that, you can take that’ and out they go” (P3). In her ideal situation, she would retain her agency in terms of decision-making about her possessions. Another participant recounts her positive experience with a professional organizer, stating:

[T]his organizer came to help me... she was really very good. She really did go by the principle of we'll look at something and we'll say 'I might get rid of this' and put it one place or 'I [emphasis] will get rid of it' and put it in another place, you know. She followed that and she wasn't real strict as far as that was concerned. She gave me leeway to think if I was going to get rid of it definitely she let me think, it wasn't like zip into the box... (P2)

Again, this participant echoes the importance of retaining her autonomy when it comes to decision about her possessions.

However, participants in this study also indicated discomfort with losing control of the larger process of intervention imposed by other people or agencies. One participant articulates that "it's not helpful to take control" (P4) in general for people who hoard. For her, the experience of receiving an eviction notice was tantamount to having a gun put to her head, saying, "You can't get anything done until the guy puts the gun down. And that was really very much what happened to me is they put a gun to my head" (P4). An eviction notice was the ultimate source of control over this participant, not just over her decisions about possessions, but over her life as a whole. The eviction notice resulted in paralysis on this participant's part, grinding her life to a halt as well. She characterized a helpful intervention as "someone [who] can come and say 'well what can I do for you?' and whichever way I start walking, they'll walk with me" (P4). This participant indicates the necessity of not having others take control over the situation, but providing support throughout the process. A key informant reiterated the need for client's who hoard to remain in control of the situation:



I think the most helpful is still them feeling like they're in control. That they have some say, actually that they have a lot of say in what happens to their stuff. Because I think that you see more changes [pauses] for the most part, more changes in people that are taking part in the process... So letting the person make that decision I think is what really helps them through the process, if they feel like they're in control. I think that's the biggest thing that I've kind of learned. (KI1)

### *2.1.2 Threats and consequences (fear of eviction)*

Consequences are inevitable when discussing code enforcement and eviction in a hoarding situation. Code enforcement agencies such as fire prevention and by-law, as well as landlords, can enact consequences due to non-compliance. As discussed earlier in this chapter, fire prevention officers are permitted, in extreme cases, to enter homes and remove items to reduce the combustible load in the dwelling. Similarly, landlords may be able to evict a person who hoards if odors, noise or other problems infringe on the reasonable enjoyment of other renters in the building. In many cases, participants experienced the consequences outlined by code enforcement or housing workers as both threatening and frightening.

One participant explains "it was frightening because the superintendent kept threatening 'If you bring [emphasis] anything in, whether you buy it or you bring it from storage, you're out of here in seven days'" (P2). In this case, this participant clearly expresses the fear of losing her housing. The issue of the limits of authority of these workers is discussed later in this chapter. Another participant explains how she felt when she was given a deadline for completing tasks for fire prevention:

I found it very hard to function. I really stopped taking care of myself in bigger ways than the first time he [fire prevention official] came, like when he put that date out there... I think 'cause the task was so monumental [pauses] that is just overwhelmed me, too much. (P3)

Like the other participant's analogy of a "gun to the head," the consequences of non-

compliance were sufficiently paralyzing to this participant, to the point limiting her ability to make gains with the physical requirements made of her. Another participant describes the fears associated with losing her housing:

[I]t's the threat of I'm not going to have housing at all because my stuff's not going to fit and I'm going to be lost in this process and I'm just going to run away. I'm just going to not be able to cope...(P6)

She expresses the sense of being overwhelmed and the potential of being lost within the “system”, questioning her ability to cope. Similarly, another participant says “I was worried about what I was going to do and whether I was going to have to hunt up another place to live... But as far as them coming in [for inspections], I had been warned. I accepted that” (P2). Despite resigning herself to the inspections of her home, she still expresses fears about the potential consequences.

Key informants also spoke of how paralyzing the fear of eviction is for some clients who hoard:

She had told me how bad it was, and she said she wanted to work on it, and that she wanted to work with me, but she didn't want me to go to her house because she was scared. So, that's kind of what I think people do to try and... keep themselves housed because I think [emphasis] somewhere inside themselves they [emphasis] know how bad it is, they [emphasis] know it's an issue, but they can't get past the anxieties to actually resolve the problem. (KI1)

### *2.1.3 Clear expectations and definitions*

Participants highlighted the importance of being given clear directions about the rules and regulations to which they are being asked to comply. One participant explains the difficulty with ambiguity:

[In] the letter they gave me saying ‘we’re concerned that your living conditions unsafe’ they listed a bunch of things that they said were wrong. But they didn’t give me a finish line ‘if you do this, it’ll be okay, if you do that it’ll be okay’. (P4)

This participant highlights the importance of the clarity of regulations through her implication that the demands will be never-ending in nature, thereby denying her a sense of security. One key informant echoed this perspective, stating:

I would guess, as a human, [it] would be very overwhelming. And so everything else that was talked about after, could be just, you know background noise in the back of his head, and he's panicking thinking 'oh my gosh, oh my gosh,' so that's why it's important for me to make sure that it's all in writing and he knows what the steps are, and what the timeframe is. (KI3)

She empathizes with the sense of being overwhelmed experienced by clients who hoard, and expresses the need to work closely with the client in identifying what the next steps are very clearly.

One participant recommends that people who hoard “find out the boundaries to which you have to cooperate” (P3), indicating that people who hoard should have clear guidelines about what is expected of them, as well as the limits of authority of the workers involved, as discussed later in this chapter. Similarly, another participant explains, “they didn't know what laws I was breaking but they kept coming back and saying... they had to do this, it was ministry requirements. They [emphasis] never showed me what ministry requirements” (P4), questioning the legitimacy of the requirements to which she was being held accountable. Ultimately, clear definitions and guidelines as to expectations not only provide a concrete goal to work towards, but a sense of security for participants. The reward of an accomplishment, or having less (or no) involvement from workers could serve to motivate people who hoard to work towards these goals.

#### *2.1.4 Deadlines and timeframes*

One of the techniques used by code enforcement officials and housing workers in particular, is to assign a timeframe or a deadline for a particular task. Participants' reactions to the timeframes imposed by workers were varied, although most alluded to the overwhelming nature of having a deadline attached to the daunting task of sorting, organizing and discarding. One participant states "I found having that date, that final date felt like that's the day you'll be hung at noon on, from the scaffold until you die" (P3), indicating the stress of the finality of a deadline for the completion of work. She went on to say "This final date looming over you.... it stressed me out to the point where I really found it hard to function. Even, like, other things, too" (P3), demonstrating that the deadline looming had the opposite effect than was intended, of hindering progress rather than advancing it.

Another participant indicates that the social service workers he engaged with were more flexible about deadlines:

Well I asked [name of worker] one time and she said 'you have to get this done by a certain day' and I said 'well what happens if I'm not able to do that?' and she said 'oh well we just [laughing] put another date on it'. (P5)

While this tactic of extending deadlines may seem counter-productive, it may help to mitigate the paralyzing pressure that participants experienced by having to adhere to strict deadlines. Meanwhile, another participant discussed the nature of the sorting and organizing work, stating, "it's like however much time you have is how long it takes to clear stuff out [laughs]. It's not as though I would have started a year sooner and finished a year sooner. Because there's no end" (P6). She identifies the cyclical nature of sorting, organizing and discarding, whereby items enter the home and have to be constantly

assessed, categorized and stored appropriately or discarded. Moreover, this participant identifies the paradox of assigning a firm deadline: with one the pressure is paralyzing, but without one, the process is both infinite and perpetual.

Conversely, one participant identifies the need for a deadline with regards to the eviction process:

It was like a horrible, horrible cross-examination by the prosecution that went on for three years and there was no finish line. There was no end of the court session where the judge bangs his gavel and says 'okay I've made my decision. You leave her alone or else you're out'. There's no finish line. (P4)

For this participant, the ongoing involvement of workers was more stressful. She wanted finality and an end-date that she could work towards.

Key informants discussed different strategies surrounding assigning deadlines for tasks:

I've dealt with people for I think up to eight months.... [After working with that client] was probably when I said... 'enough is enough here'. We gotta figure something else out. But usually if I come back in thirty days and I see they've made good progress I will schedule another appointment in another week and see how it's going. And I've probably gone up to two months then. (KI8)

[G]enerally what I try to do with them too is not to overwhelm them. I always try to start with an area, so I'll say, 'You know what... we've got all this to deal with, what do you think you could get done for me if I gave you a week's time and came back next week and followed up with you...?'... [I]f I come back the following week and they've done that, and I can move on to another section of it, and again, as long as I'm seeing progress, I don't care if it takes me a year to work with somebody, I'll do that. It's when that progress stops and then I'm continuing to get complaints that then, you know, I may have to be a little bit more heavy-handed and just say, 'Okay, here's a letter, here's your deadline'. (KI6)

While there was no consistent, single approach taken by key informants, generally speaking, as long as progress continues to be made, the workers involved will extend deadlines and continue to work with the client.

### 2.1.5 Chipping away

Several participants spoke about the process of sorting, organizing and discarding and the tactic of “chipping away” at the accumulated possessions, bit by bit. One participant identifies “Chipping away at the problem was [emphasis] huge. So that I was really making a lot of progress” (P4). Frost and Hartl (1996) identify common problems for people who hoard: difficulty making decisions, as well as with categorization and organization. Given these two components of hoarding, it follows that the process of sorting and organizing possessions, a process requiring a great many decisions, would be slow and time consuming for people who hoard. Indeed, one participant notes “it meant we did have to slowly go through every box and shelf and plastic bag. Every stack of whatever... Trying to do that perfect right decision for every item” (P6). For some participants slowly working through the problem, taking time to recover when they became overwhelmed by the process, worked well. One key informant notes the importance of change over time, emphasizing that the process is slow:

[A]t the beginning we thought that too, right? ‘Oh it’s gotta be done next month’. We’re realizing that it does take time. And you know as long as we’re working with the tenant and things are improving, you know the fire department everyone is okay with that as long as there’s change over time. (KI4)

Meanwhile, one participant reported that a “clear out” or a team approach would be beneficial. One participant reports:

[T]hey said this has to be done and I agreed [laughing] with them. ...[T]hey proposed a couple of different ways of doing this and the one way, which I jumped on right away, was to empty out most of the apartment. To be able to start from scratch bringing things back. You know, and, I jumped on that. I could see that was the most logical thing to do. Just get rid of everything [laughing] and they sure did! (P2)

It should be noted that in this situation, her possessions were not discarded, but kept in off-site storage. Forced clear outs have proven to be detrimental to people who hoard. In three separate cases in Nantucket, Massachusetts, the individuals died within a few weeks of their homes being cleared out as a result of the drastic changes (Bratiotis et al., 2011).

Key informants confirmed the negative consequence of forced clear situations in Waterloo Region. One key informant reports “[W]e’ve realized that our clean sweep [in] a week does not work with hoarders. Because hoarders, they want to be there for every single decision about everything. And often, [it’s] too overwhelming to have a team”

(KI7). Other key informants echoed this:

[If] I go in and take their stuff[,] I’m just gonna probably make it worse, right. ...[W]e’ve got a lady that fire cleaned out her house, we did the outside a few years ago and she’s probably hoarded [emphasis] twice as bad. And to this day, I mean I get comments, I get along with her very well, but she’ll from time to time say to me, she feels like we raped her. (KI6)

[Following a forced clear out situation] I actually had to call [support worker]...[to suggest that they] keep an eye on [the client]... she was telling me she just wanted to die and it was awful, it was really awful. She was so distressed... she just wanted to end her life (KI8)

While a forced clear-out may address the physical safety risks that hoarding can cause, they can have potentially negative, and sometimes life-threatening, consequences for people who hoard.

#### *2.1.6 Limitations of services*

Most participants had engaged with different services that offer physical assistance, such as cleaning services through social service organizations, cleaning companies, laundry services, professional organizers and others. Participants spoke about the limitations with these services. In some cases, participants were not able to access

these services at all. Most services have limitations regarding the environments in which they will work. One participant expressed her frustration with these restrictions:

“[Speaking as support worker] ‘well I can’t get anybody because they don’t come in if there’s clutter.’ Well, what the hell good is that?” (P1). Another participant spoke about the lack of options available on a limited budget: “it’s just hard ‘cause there’s not a lot of low-cost supports out there... [T]he amount of money you can get for help isn’t that much, right? That’s, I guess that’s the biggest problem” (P3). Despite her willingness to employ a service that could assist with the sorting and discarding of items, she is not able to afford it. While one key informant, a professional organizer, said that her company occasionally offers pro-bono services for people with hoarding problems, she explained that generally these are consultations about strategies rather than hands-on sorting and discarding.

One participant struggled with the disinterest on the part of the people helping to sort his possessions with the stories attached to his possessions: “I would tell the story if they were interested... I mean these people are not interested in what I have to say about this particular item” (P5). He says that the workers are either unwilling or unable to spend time listening to his stories about his possessions, which appears to be a vital part of the process of sorting and discarding for him.

Participants were conflicted over services that supported the physical aspects of the process. One participant stated, “I certainly could have benefitted from more hands-on somehow” (P6), referring to a service that perhaps could have assisted with more sorting, organizing and discarding. However, this participant also recounted her feelings after having someone who did help:



I admitted [to him] ‘yes it was [a positive experience] but I felt [emphasis] so bad afterwards and it was so horrible to just have somebody beside me’ even though they’re being pleasant, my experience is somebody must be thinking I’m such a horrible person to have let my space get like this. So it took a lot of recovery time...(P6)

She exposes the double bind of needing the physical support, and yet resisting that support because of the difficult feelings that arise as a result. Another participant echoed this predicament, explaining “when [support worker] and I cleared a three-foot square space on my floor I spent the night throwing up” (P4).

Key informants confirmed that this has been a complex struggle in many of their roles as well. One key informant recounted a situation where she had worked with a woman with a hoarding problem, who had found having a team of workers assisting with sorting and organizing to be too stressful, and halted the process mid-way through. She reported, “We still go back and see her regularly and she’ll say, ‘I’m ready to get organized, come on over’. And we go over and we go through some of the stuff, some goal setting, and then she kiboshes it” (KI7), explaining the cyclical nature of this dilemma.

## ***2.2 Organizing Theme: Rights of People Who Hoard***

While participants and key informants did not generally directly address the issue of rights of people who hoard, this theme emerged through the discussion of the need for advocacy and the limits of authority of workers. Due to the highly stigmatized nature of hoarding, as well as the potential for infringement on the rights of others, participants spoke about the need for acknowledgment of their rights.

### 2.2.1 Advocacy

Some participants identified advocacy as playing a part in maintaining their housing. One participant described reaching his breaking point in terms of complacency with the process: “I got to the point where I had to stand up for myself a little bit here” (P5). Another participant described her experience of trying to advocate for herself within an agency:

I’m supposed to speak up without [emphasis] crying to explain my situation and defend my position here and knowing it’s against what they’ve already decided for me because as much as I can thinking, in [emphasis] theory, people need to stand up for themselves and people need to be assertive and that sort of thing, for me to be the one to do it, I’m such a sensitive, emotional person so that was horrendous... (P6)

This participant found it very difficult to advocate for herself, despite her belief that it was the right thing to do. Meanwhile, another participant identified the need to have an advocate speak on her behalf:

I went to court and when it was my turn to tell my side of the story, I froze, I completely froze. I couldn’t say a thing. I had a stack of files that I could have just read, but I couldn’t do that so basically the landlord’s story went undisputed and I was evicted from that...apartment because I froze... (P4)

The paralysis she experienced in the court room in a previous eviction proceeding ultimately led to her losing her housing. She went on to say:

I have to...decide which way down the highway we go but I gotta have someone else holding the steering wheel with their foot on the gas. ‘Cause I’ll hit the brakes and swerve off in the ditch. Myself, that’s what my [diagnosis] does for me. (P4)

She makes an eloquent analogy to explain the need for advocates not only within the legal system, but within other systems (medical, housing, mental health, etc.) involved in hoarding. While there is a need to have control over the choices she makes, it is important to have an advocate who is able to speak up for her at times. This participant

explains that advocating for yourself is difficult: “trying to do your own lawyering is kind of like trying to do your own tonsillectomy: no matter how good you are at it, it’s awkward” (P4).

Key informants confirmed the need for advocacy in cases of hoarding:

the landlord... he would push the littlest thing. He would say ‘well what about this? She needs to get rid of this.’ And [name of fire prevention official] would be like ‘...that’s not anything to do with fire code, so there’s nothing you can say about it, as a landlord’. (K11)

Despite the fear of fire prevention officials that many people who hoard feel, this key informant described the fire prevention official as advocating for him by reminding the landlord of the limits of his authority in the situation.

### *2.2.2 Limits of authority*

Participants described situations where they felt that social service workers, code enforcement officers, housing workers, and even family members had overstepped the limits of their authority. In some cases, it was a clear violation of the participant’s rights. One participant explains:

I had to go out and buy some things 'cause everything was gone, and... I wasn't [emphasis] allowed to go over to the locker and the superintendent laid that down. So I had to sneak things in, actually, is what I did. (P2)

In this situation, her superintendent had forbidden her from bringing anything into her home following the removal of a large number of things. While the superintendent clearly had concerns about re-accumulation, it is well beyond the limits of their authority to prevent a tenant from bringing items into their home.

One participant describes a worker breaching confidentiality: “he was very well aware that they weren’t supposed to talk to me, that they should have answered every question ‘I’m sorry that’s confidential’. And he knew they were violating the law when

they talked to him” (P4). Bratiotis, Schmaslisch and Steketee (2011) caution against workers overstepping their authority, and in situations where legal warrants needed, suggest that all agencies be listed on the warrant.

However, one participant describes:

I just got to the point where I just couldn't handle a visit that day so then I'd skip out and just go out of the building and they can't get in to my apartment without having my permission, me being there, or me letting them in... (P5)

This participant uses the limits of authority to protect himself emotionally and psychologically, ensuring that the expectations on him do not become too taxing.

One key informant specified that the limits of the authority are based specifically around safety, and that workers can require few changes outside of safety concerns:

...[Y]ou can't tell somebody how to set up their house or how to live. So you can, [pauses] make sure that everything is up to fire code, you can make sure that everything is safe... But if they want to have a little bit of a pile of clutter in the middle of their living room, who are you to say that they can't? ...[N]ot everybody's house is going to be like a *Style at Home* magazine. And you really have to realize that when you are working with these people, it's not what it's going to be. If they feel safe with a little bit of clutter around [implying that it is acceptable]... (KI1)

This key informant explains the importance of not imposing personal values and beliefs onto clients who hoard, beyond health and safety concerns.

As outlined through the organizing and basic themes presented in this section, participants identified a number of ways in which they found the structure of services impacted their ability to maintain their housing. A structure and guidelines within which services can operate offer a number of positive impacts for people who hoard. Participants also highlighted the need to have their rights respected by workers involved in their cases.

### ***4.3 Chapter Conclusion***

In summary, I have presented tables outlining the three forms of numerical data collected for this research: CIR ratings of the homes of participants; CIR ratings of the average home with hoarding as indicated by key informants; and the number of hoarding cases seen by key informants. I have also presented contextual findings regarding Waterloo Region's response to hoarding and the eviction risks and other regulations that affect people who hoard. Finally, I identified two global themes in the participant data: 1) Building a Helping Relationship with People Who Hoard; and 2) Building a Framework within which to Provide Service. Each of these global themes contained organizing subthemes as well as basic themes within the organizing themes. The findings demonstrate ways in which interactions and relationships at the individual, micro level can impact the way people who hoard interact with the larger, social systems in which we are embedded.

## CHAPTER 5

### DISCUSSION AND CONCLUSION

In this final chapter, I offer first a summary of the study, and then explore how the findings of this research resonate with the existing literature on hoarding and eviction prevention. The latter is followed by sections dedicated to the limitations and implications of the study and a final conclusion

#### *5.1 Summary of the Study*

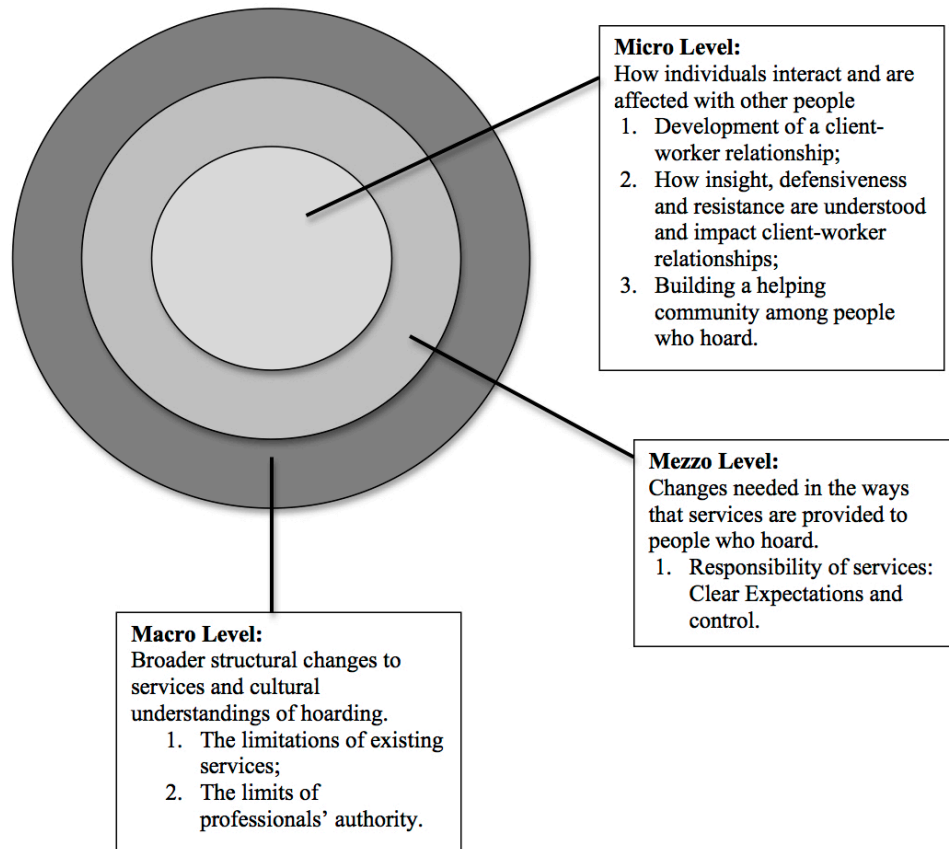
In the introductory chapters of this thesis, I presented a rationale for this research, outlining the physical safety risks that can result in eviction for people who hoard, and summarizing the need for further research on the topic. In reviewing the existing literature on hoarding, I found that previous research has focused on a medical model, outlining the diagnostic criteria for hoarding disorder, and other mental health diagnoses that can result in hoarding behaviours. I also presented the impacts that hoarding can have on different levels, such as families and the broader community.

A pragmatic paradigm was chosen for this research, in the hope that practical results and suggestions would be generated from the data. I have utilized general systems theory as a theoretical framework to understand the interactions between individual, (micro) experiences of people who hoard, and the larger (mezzo and macro) social services and systems within which they are embedded. I selected a qualitative case study research design in order to explore a relatively new area of inquiry, and I focused on a geographic region with the expectation that results from this research may be applicable in other areas of southern Ontario.

In the previous chapter, I outlined the findings from participant and key informant interviews, which were analyzed thematically to uncover patterns from the narratives of both groups. Two global themes emerged: 1) Building a Helping Relationship with People Who Hoard, and 2) Building a Framework within which to Provide Service. Each of these global themes contained within them two organizing themes, and a number of sub-themes that represent the specific topics participants addressed in their interviews. Given that this is a case study, I also presented contextual findings specific to Waterloo Region, outlining risks of eviction or housing loss.

## ***5.2 Discussion of the Findings of the Study***

I have used systems theory as a framework by which to organize the discussion of the findings of this research. The first section provides a discussion of the findings and implications at the individual, micro level, the second section a discussion at the mezzo level, and the third section at the macro level.



*Figure 2. Eviction Prevention for People Who Hoard at Each Systems Level*

Additionally, I have incorporated an anti-oppressive perspective into the discussion of the findings of this research. As noted earlier, the current research and literature about hoarding has mostly taken a medical model perspective. The medical model makes clear delineations between the sick and healthy, and the expert and the patient. An anti-oppressive practice approach complements not only systems theory, but a strengths-based perspective of people who hoard. Larson's (2008) analysis incorporates an anti-oppressive practice approach in mental health work. He identifies that "anti-oppressive approaches move away from reliance on biomedical theories and incorporate holistic, strength-based, and structural perspectives" (p. 46-7). Anti-oppressive practice "involves self-reflection, an understanding of power and oppression and one's place in



that oppression” (Larson, 2008, p. 41). As such, despite the use of a pragmatic paradigm, I have used Larson’s work to inform my discussion of the research findings.

### *5.2.1 Micro level analysis of individual interactions*

This section outlines the implications of services at the individual, micro level. I use Bronfenbrenner’s understanding of the microsystem, whereby the system is composed not only of the biopsychosocial person, but the person’s interactions with others (Lerner, 2005). As such, three overarching topics are discussed:

1. Development of a client-worker relationship;
2. How insight, defensiveness and resistance are understood and impact client-worker relationships;
3. Building a helping community among people who hoard.

Each of these topics has ramifications in developing a productive relationship that contributes to the maintenance of housing for people who hoard.

#### *5.2.1.1 Development of a client-worker relationship;*

In *The Hoarding Handbook*, Bratitotis, Sorrentino Schmalisch and Steketee (2011) review some basic principles for professionals working with people who hoard. Their recommendations, while not identical, are largely congruent with the findings of this research. In these findings, it was apparent that how participants’ perceive their treatment was important, both in accepting help from service providers and in determining the effectiveness of that help. Respect, non-judgment, and authenticity were essential in developing a relationship.

Similarly, Bratitotis et al. (2011) cite using respectful language, and language that reflects non-judgment, especially with regards to the person’s possessions, as important

aspects of visits to hoarding clients' homes. Worden et al. (2014) recommend that interventions for people who do not perceive their hoarding behaviour as problematic should be "long-term and outreach-based...[and] should focus on the development of a supportive, non-confrontational therapeutic relationship" (p. 251). Similarly, Lambert (1992) cites "common factors" (p. 97), such as empathy, warmth, and acceptance, account for as much as 40% of clients' change, demonstrating the efficacy of these characteristics in a therapeutic setting. While not all workers will be involved in a therapeutic capacity, this research demonstrates the importance of these factors in building a relationship with a client. While their suggestion is aimed at a specific "type" of hoarding client, the findings of my research support the use of these strategies for use with all people who hoard. This suggests that at the individual, micro level, their interactions with workers are important in the development of a helping relationship.

The context of the relationship between workers and the person who hoards has proven to play a role in how that relationship develops and unfolds. In the *Hoarding Handbook*, the authors suggest that interdisciplinary task forces or committees designed to address hoarding cases take a "carrot and stick" approach, whereby code enforcement and other officials with the authority to impose limits and consequences are the "stick", while social services take on the supportive "carrot" role (Bratitotis et al., 2011). The authors suggest that this "arrangement provides needed encouragement while recognizing the seriousness of the situation that requires compliance that is difficult for the hoarding client" (Bratitotis et al., 2011, p. 31). This approach has been accepted as a method by which to achieve compliance to health and safety regulations (Tompkins, 2011). Thus,

Bratiotis et al. (2011) suggest using the context of the worker-client relationship to the benefit of professional goals.

One key informant spoke to the context of the client-worker relationship explicitly, saying:

I don't think I've ever had anybody who's wanted me there, so the impression I get is that they will often... satisfy me because they don't feel they have a choice. Whereas with [name of support worker], they can say 'I don't want to work with you', and she doesn't really have any recourse there so, generally my impression is that they'll work with me to do what they have to in order to get rid of me. But not because they're trying to, you know, they recognize that there's an issue. So, 'What do I need to do to get you off my doorstep and not have you come back. But I'm not interested in being your friend', so to speak. (KI6)

This key informant, a code enforcement worker, outlines the attitude from the clients she has had who hoard, both towards her, and as compared to someone who plays a supportive role. This suggests that the role of the workers involved can be a factor in people's willingness to engage in changes from the outset. Since code enforcement and housing workers are typically perceived as threatening, there can already be hesitancy to trust and to work together, further compromising the person who hoards' housing security.

In another study, Frost et al. (2000) showed that 32% of cases involving code enforcement were resolved with willing cooperation; in 28% of cases the person reluctantly agreed to improve conditions but did little to change the state of the home; and in 40% of cases the individual refused to cooperate, had possessions removed by the city, and were then monitored by the health department. While this study does not address eviction specifically, it indicates the high level of opposition that individuals who hoard can have in cooperating with code enforcement agencies.

Frost et al. (2010) describe another study in which research assistants asked participants to discard an item they would otherwise not, while monitoring the emotional reactions of the participant. However, the outcome of the research was not what the researchers had anticipated, as participants discarded items with little or no difficulty (Frost et al., 2010). Some participants seemed to enjoy the study, and one participant later notified the researchers that he went on to clear out his entire home (Frost et al., 2010). The researchers postulate that the context of discarding, with no pressure, made the task easier for participants (Frost et al., 2010). While the research assistants in this study still sought to have the participants discard items, the unpressured nature of the relationship was instrumental in whether the participant felt comfortable doing so.

The above is an example not only of where psychological resistance (see section 5.2.1.2 below for more information) could have an effect on the ability of people who hoard to be compliant with housing regulations and code enforcement requests, but how the context and nature of the relationship between the person attempting to help the hoarding client can affect the outcome. The findings in my research point specifically to the importance of the nature and context (see 1.2 *Nature and context of relationship with workers* and subsections) of a hoarding client's relationship with the workers involved in determining whether they were willing to accept assistance, and ultimately in maintaining their housing. Thus, the nature and context of the client-worker relationship can have a powerful effect on behaviour and the end result of the interaction.

#### *5.2.1.2 Understanding insight, resistance and defensiveness*

The language in mental health services surrounding *insight*, and the evaluation of people who hoard as “lacking” in this area is generally a pejorative and paternalistic view

of this group (Frost et al., 2011; Frost et al., 2009; Grisham et al., 2008). However, Worden et al.'s (2014) linking of *defensiveness* to the concept of *psychological resistance* helps to explain how this stigmatizing judgment has developed. Essentially, the principle of psychological resistance holds that the more restricted a person feels, the more resistant that person will become in order to feel as though they are in control (Brehm, 1966 as cited in Worden et al., 2014). Given that people who hoard are often hounded about their accumulated possessions for years by family members, housing workers, social services, code enforcement and others, it is understandable that individuals can develop a defensive stance.

Correspondingly, participants in this research spoke about the paralysis of deadlines and timeframes imposed by housing workers and code enforcement agencies involved in their cases. While none of the participants described being defensive when asked to comply with regulations, it could prove useful to understand the pressure to conform to deadlines through this lens, and perhaps to understand defensive behaviour as a reaction of fear on the part of individuals who hoard. Bratotiis et al. (2011) write, "Service providers can minimize conflict and obstructionist tactics considering the behavior to be the person's best attempt to protect himself or herself against uncomfortable or painful feelings" (p. 21).

#### *5.2.1.3 Building a helping community among people who hoard*

While it may appear that shame could be a motivating factor in changing hoarding behaviours, shame researcher Brené Brown (2008) writes unequivocally, "You cannot shame or belittle people into changing their behaviours" (p.1). The findings of my research support Brown's work, as participants emphasized the need for non-judgmental,

empathetic relationships (see *1.1 Treatment of Person* and subsections). Brown (2008) highlights the need to speak about feelings of shame in order to develop what she terms shame resiliency, as well as the importance of others responding empathetically when hearing about another's experience of shame. Brown (2008) explains that feelings of shame will increase the more we hide our shame from others, and writes, "Its survival depends on remaining undetected; therefore it seeks silence and secrecy" (p. 155).

One participant in this research described a possible avenue for physical support, whereby individuals with hoarding problems could help others who hoard with sorting, organizing, and discarding. She explained:

You'd figure there's less judgment because they probably volunteered for this because of some reason they get it. So I would be willing to go into someone's home and then have [support worker] telling them 'she's been there, she understands, she's gonna be the last person judging you for what [emphasis] your situation is, so very much a pass it on structure would really work for me 'cause I'd be more inviting to those people in my home and I would be willing to pass on the help given to me... And really if I was helped [stammers] and not just a professional like [support worker] but met someone who volunteered their time and help and just wanted me to get through this difficult [emphasis] task that needed to be done then I would be very willing to move on and say 'I can gift that to somebody else' you know. (P6)

This participant clearly identifies the need for support from not just a professional source, but from people who can truly understand and empathize with her experience first hand, and who will, as a result, not pass judgment. She ultimately describes the basis for an on-going program structure, suggesting that a core group of people would continue to support people with hoarding problems with the physical help they need, and each person who receives help is required to help with the next person's home. This practical suggestion would not only promote a sustainable program model, but would create a

sense of community and belonging among participants in the program, ensuring an atmosphere of trust and mutual support.

There is anecdotal evidence to support such a model: a Toronto-based organization called Fresh Start exclusively employs people who are or have been consumers/survivors of mental health services to provide cleaning services. Fresh Start receives funding from the City of Toronto to assist with cleaning in hoarding situations where the individual has been served an N-5 eviction notice (personal communication, D. Anderson, May 14, 2014). While employees at this organization may not include people who struggle with hoarding, this example demonstrates the viability of this business model.<sup>3</sup> Similarly, at a peer support group for people who hoard, some of the group members offered to help with sorting and removing items from one of their fellow group member's homes. They were successful in downsizing the number of possessions to the satisfaction of the local fire department (personal communication, K. Hodder, November 28, 2014). Research suggests that due to emotional attachment to possessions, individuals who hoard experience more difficulty in sorting, organizing and discarding their own possessions than those of others (Wincze, Steketee & Frost, 2007). A program like this might even allow individuals who hoard to strengthen their sorting, organizing and discarding skills, helping them to address their own hoarding, and allowing them to maintain their housing with greater ease.

Brown (2008) writes of the importance of creating a culture of connection in order to develop resilience to the negative effects of shame. She argues that the process of reaching out to others is transformational, and can be inspirational in creating further collective change. In order to create change:

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<sup>3</sup> For more information about Fresh Start, see <http://freshstartclean.com/>

[I]t's important to realize that not all of us are going to engage in political action, advocacy or even small group efforts. Some of us may create change by changing the way we interact with people or changing our relationships. Others may raise critical awareness with friends and family members. (Brown, 2008, p. 131)

The model suggested by one of the participants (P6), whereby micro-level connections to other individuals could provide the transformational change needed, addressing the physical and emotional needs of people who hoard and enabling them to make the changes needed to maintain their housing.

### ***5.2.2 Mezzo Level Analysis of Services***

This section outlines the changes needed at the mezzo level, whereby workers involved in hoarding cases need to change the way they provide services in order to be effective in helping people to maintain their housing. There is a single section at the mezzo level: Responsibility of services: Clear Expectations and control.

#### ***5.2.2.1 Responsibility of services: Clear expectations and control***

Participants and key informants alike stressed the need to outline the expectations of housing workers and code enforcement officials clearly (see 2.1.3 *Clear expectations and definitions*). Clear expectations provide a goal, or a “finish line” as one participant (P4) called it, towards which participants can work, allowing the possibility of 1) a sense of accomplishment at the end; and 2) a sense of relief at complying and therefore not having the looming threat of code enforcement or housing worker involvement. Bratiotis et al. (2011, p. 92) recommend dividing the tasks needed for compliance into smaller, manageable tasks, provided verbally as well as in writing, and followed up on regularly. One key informant echoed this recommendation:



I think baby steps for them, giving them [emphasis] small, attainable tasks. Not saying ‘you need to have this cleaned up in six weeks’, and coming back but having sort of shorter term goals. An accountability, where they know that I’m coming at such-and-such a time you know, three days, five days, whatever it is. For the one gentleman we did twice-weekly inspections for the first two weeks and then weekly inspections after that and now we’re sort of at the monthly stage and we’ll kind of see how that goes. (KI3)

One of the key informants interviewed for this study indicated that the Ontario Fire Marshal had recently increased the level of detail outlining what the infraction is and what needs to be done to remedy it. However, this revision was not only related to hoarding situations, but across the board for cases that progress to court proceedings. Thus, clearly defined expectations by service providers are needed at the mezzo level to help prevent people who hoard from being evicted.

Participants cited maintaining control over their possessions, and over eviction and other regulatory process to be of importance (see *2.1.1 Control over process and possessions*). The literature supports the notion that people who hoard are often very attached to their possessions, and are therefore uncomfortable with others handling and making decisions about their possessions (Frost & Hartl, 1996). However, there is less written about the need for control over larger processes such as eviction or an order from the fire department. The findings of this research demonstrate the need for clear expectations and definitions with regard to these larger processes (see section *5.2.3 Control over possessions and process*). While many participant responses were directed at clarity around what needed to be discarded or the level of clutter that could remain in the home in order to achieve compliance, there was also the need to understand what would happen next. This understanding was key to assuaging feelings of fear and anxiety about participants’ housing situations. Bratitot et al. (2011) note, “with the involvement

of multiple different services, it is important to ensure that the client remains at the centre of the response” (p. 36). The person who hoards should be a key player in determining the next steps. Similarly, Tompkins (2015) outlines the importance of client involvement in a harm reduction approach: “Harm reduction assumes that people have the right to make choices and, as such, to participate in solving their severe hoarding problem” (p. 54). Therefore, both the existing literature and the findings of this research support the need for control over decisions about discarding and the broader eviction process at the mezzo level.

### ***5.2.3 Macro Level Analysis of Policies and Services***

This section outlines the broader structural, macro level changes to services as identified in my findings and in relation to the existing literature in two broad sections, each with two subsections:

1. The limitations of existing services;
2. The rights of persons who hoard and limits of worker authority.

#### ***5.2.3.1 Limitations of services***

Participants identified several areas in which the services they utilized were limited as to the kind of help they could provide (see *2.1.6 Limitations of Services*). For example, several identified that there were no existing or few low-cost or free services to assist with de-cluttering, sorting or organizing. Key informants expressed frustration with the limitation of services available in different areas. One key informant commented on the lack of mental health supports: “[change is] not happening because they’re not getting therapy. Like, assistance with mental health” (KI8).

Likewise, one key informant explained the circumstances under which a client was evicted:

[I]t was actually more of a crisis situation, they had been [given an eviction notice]...but they ignored it, so... they didn't actually get the support they needed. ...[T]hey had come to me at the end of their eviction notice, so they really only had 72 hours and wasn't really a good timeframe for getting done what needed to be done. Also severe mental health [was an issue]... this person had been in and out of housing and on the streets so [it was] somewhat of a norm for her to go from a housing situation to a homeless situation. (KI9)

Not only in this situation were the mental health considerations beyond the scope of the worker, but the timeframe in which to address the problem was simply not realistic. Both of these key informants are speaking to the lack of mental health resources available in Waterloo Region, specific to hoarding concerns. While literature suggests that a CBT program specifically designed to address hoarding has seen some success (Steketee et al., 2010), there does not appear to be any therapists locally with the background and training to provide this type of treatment. The availability of such treatment could be important for supporting clients who wish to explore more intensive individual therapy, minimizing recurring issues with housing instability. The lack of appropriate available services in Waterloo Region suggests that there is a larger cultural and political problem, in that eviction due to hoarding has not been recognized as an issue worthy of attention and resources.

#### *5.2.3.1.1 Limitations of harm reduction approach*

The literature suggests that a harm reduction approach can be helpful to individuals faced with eviction or loss of housing, focusing on the symptom (the accumulated clutter) rather than the distress or impairment caused by the hoarding

(Tompkins, 2015). However, one participant discussed the limitations of the counselling she attended:

I was already in counselling for other issues so. Between, with my relationship with my [family member], she/he and I were there together and with her/him coming back to move in with me instead of [family member] and just my own dealing with my [family member] and all the upsets she/he [emphasis] triggers for me, trying to add in one more area of counselling, it's like where do you fit it in priority-wise? (P6)

She identifies the downfall of harm reduction-based interventions propelled by code enforcement and housing workers. Deadlines and timeframes imposed by officials ensure that the physical safety risks are addressed in a timely manner, a crucial aspect of the work that they do in ensuring the safety of the person, and in some cases, of the general public as well. However, in assigning stringent deadlines, the process focuses exclusively on the physical elements of hoarding, perhaps at the expense of the psychological underpinnings. Even for a person who is already attending counselling, there is no time to address the larger psychological and emotional aspects of hoarding, particularly if the individual is already coping with other difficulties. Tompkins (2015) writes “HR [harm reduction] assumes that the person with *severe* hoarding is not interested in changing these patterns, may not be capable of changing these patterns, and to try to change these patterns may increase defensiveness and help refusing behaviour” (p. 52). While the harm reduction approach can help to ensure that the individual adheres to regulations and maintains their housing, it is possible that without addressing the root problems, the person will find themselves again in conflict with housing workers and code enforcement officials as a result of re-accumulated clutter, despite their wishes to change this behaviour. As such, perhaps harm reduction is best utilized as a starting point for intervention, with further treatment and support available for people who wish

to see lasting changes in their hoarding behaviour.

#### *5.2.3.1.2 Mandated treatments and interventions*

Bratiotis et al. (2011) note, “An emerging role of the legal system is to intervene effectively with hoarding, addressing the underlying problem and establishing enduring change” (p. 130), referring to the cooperation between the courts and social service workers. The primary informant in this research noted that there has been one instance where a client who hoards has been mandated to work with her as a support service to address the safety risks in her home (personal communication, K. Hodder, January 31, 2015). This indicates that legal mandates are beginning to crop up in Waterloo Region, perhaps as a result of having a full-time worker dedicated to hoarding situations.

Mandated treatments in general are not always effective, given that clients are at various stages in their readiness to change, and practitioners often believe that the context of being mandated to treatment can result in further reluctance to participate. However, Bratiotis et al. (2011) note the importance of ongoing support and follow up in hoarding cases. This was echoed by several key informants in this study:

I think ... we try and [hesitates] let them know they can call any time. And keep that communication open, like “we’re here to help you” and “we want you to be successful and if you feel you need some more supports or anything, call us and we’re there to help” and just offer that support to them is a big help. (KI4)

...normally... once a file’s complied with, it’s closed, we don’t continue to monitor. I just do more or less because it’s only a handful of them and... I understand that it’s not just as simple as ‘okay we’re done’. (KI6)

...they would do checks every three months, the housing complex, just to ensure that things did not slip to that point again. (KI5)

Although the looming threat of code enforcement officials may prove to be stressful to some people who hoard, one key informant referred to having developed a relationship in hoarding situations:

I think too because I've been dealing with them for so long... to introduce a new person into it at this point, we'd be starting from scratch. So it's a lot easier for me to just go there and say, 'You know what? Things are starting to get full here again, we need to just start doing some work on it.' ...I've already built that relationship with them. (KI6)

Developing a relationship with the person first may help to assuage some of the fears of having a code enforcement official follow up from time to time. This situation provides an example of how one code enforcement worker operates as an agent of social control with individuals who hoard. However, she has also changed the way she operates as a representative of a larger social system to better fit the needs of the individual, ultimately ensuring that the larger system of regulation continues to function.

#### *5.2.3.2 Rights of persons who hoard and limits of authority*

While the key informants in this research appeared to have a fairly solid understanding of the limits of authority of various professions involved in hoarding cases, further education and training is needed both for workers and people who hoard to ensure that the rights of people who hoard are not violated.

##### *5.2.3.2.1 Human rights and the duty to accommodate*

While only one participant spoke about the duty to accommodate specifically, this is an area that has potentially large practice implications. Although most key informants understood that there is a limit to their authority in terms of removing items from someone's home, and the demands that they can make on their clients, they were not aware of the language and legalities surrounding the duty to accommodate. As a result of

the addition of HD to the *DSM-5*, hoarding is considered a mental health disorder, and therefore a psychiatric disability. Hoarding behaviours that are the result of another mental health diagnosis (such as major depressive disorder, or OCD) can likewise be considered a disability. As such, under the *Human Rights Code*, landlords cannot discriminate against individuals who hoard by evicting them without providing accommodation for their disability (Levitt, 2013). Accommodation can range in terms of what needs to be provided, and can be quite specific to the situation. Examples of accommodation might be extending timeframes under which to remove possessions or contacting local social services to assist with this process. Landlords have a duty to accommodate up to the point of undue hardship, which is often based on financial burden (Levitt, 2013). However, the person who hoards must also make it known that they require accommodation (Levitt, 2013).

The fire prevention officers interviewed were unsure as to whether they, too, had a legal obligation to accommodate people with a mental health diagnosis (ie. by providing extended deadlines, etc.). However, one official observed:

...I don't believe you're ever going to get compliance from a high combustible load within thirty days. Unless you've got... someone with a whole lot of help, or someone comes in and just does a great big sweep and throws everything out, and clears it out like that, it's very rare that that'll ever happen. Because, like I said, it's very overwhelming, it's very emotional, and these people have a hard time getting rid of some of these things... (KI2)

Although this official does not state it explicitly, he alludes to the understanding that in hoarding situations, extended timeframes are necessary. One participant alluded to a worker who was willing to be accommodating, explaining, “[fire prevention officer] looked around and said ‘stuff is going to have to be cleaned up or cleared out or

something you know' and he didn't write me up. I thought he was going to" (P3).

Thought it was not explicitly stated, it appears that this fire prevention official was aware of the need for extended timeframes. The duty to accommodate is a broader level at which individuals who hoard can challenge and interact with the legal and cultural status quo, demonstrating the potential for social change as a result of individual interaction with these macro systems.

#### *5.2.3.2.2 Rights of people who hoard vs. the rights of others*

Many people who hoard questioned whether their individual rights had been violated. One participant recounted, "...[T]he superintendent kept coming up here and seeing what I was doing and... every day she would come in" (P2). While landlords are allowed to inspect rental units, a daily inspection may be infringing on the rights of a tenant. Similarly, another participant described:

[The lawyer] kept telling me [yelling] 'but you have to understand that they have to inspect!' and she was [emphasis] incredibly forceful, so here they did, they managed to force their way into my home. It was extremely traumatic. I had police present. (P4)

Her description of the inspection certainly raises the question of whether the lawyer was operating within his/her authority. At times, housing workers who are involved in hoarding situations may be overwhelmed by the state of the apartment or property. Fears about liability, damage to the property, complaints by neighbours, and even job security could motivate a housing worker to act outside the bounds of their authority.

Bratiotis et al. (2011) note that although some hoarding situations can be cause for immediate concern because of the health and safety risks that they pose for family members or neighbours, there are also situations where the accumulated possessions may interfere with the person's daily life but there is no imminent risk to the person or those



around them. As a result of biases, personal preferences, and beliefs of the intervening workers, the authors recommend that workers utilize proper assessment tools to determine the severity of the situation (Bratitotis et al., 2011). The reality is that social services, landlords, and even fire prevention or other code enforcement agencies are all limited in the degree to which they are allowed to instruct people how to live. While on a personal level a visiting nurse or social worker might be appalled by the level of cleanliness in a home, unless it poses a clear and imminent danger to the person/people living there or their neighbours, there is little that can be said or done. As one key informant stated, “you can’t tell somebody how to set up their house or how to live” (KI1). However, most workers must engage in balancing the rights of the person who hoards, and their family members and neighbours. Supporting a family member, such as a child, may come at the expense of the rights of a person who hoards, but supporting the person who hoards may come at the expense of a landlord’s wishes. Taking into consideration the discrimination that people who hoard face, the careful balancing of rights provides an opportunity for broader social change.

### ***5.3 Limitations of the Study***

Given that this research was completed as part of a master’s program, there were limitations on the timeframe of this project, which, in turn, had an effect on the scope of the research.

There is concern about the potential for social desirability bias toward particular supportive interventions among participants, given that the majority of the participants had likely all received support from services providers. During the interviews, I indicated

to participants that anything they said would not be attributed to them, and if they had feedback about support services they could express this in a way that would not reveal their identity. While participants were generally positive about their experiences with services, some participants offered suggestions for improvements, indicating their comfort with providing criticism about the services.

As outlined in the methodology chapter, participants in this research were not screened for a specific diagnosis of HD. I relied on the purposive selection of potential participants, presuming that their interactions with various agencies was a sufficient indication of hoarding behaviour, regardless of diagnosis. As a result, it is possible that participants in this research had no diagnosis to explain their hoarding behaviour at all, or that participants had diagnoses (other than HD) that could cause hoarding behaviour (see Chapter 2 for information about possible diagnoses). This research is not focused on a specific diagnosis that can cause hoarding; rather, the implications of accumulated possessions and the resulting risk of eviction were primary to this research. However, Pertuse and Fonseca (2014) note the importance of ruling out a diagnosis of OCD specifically because of the difference in treatment modalities used in OCD and HD. Therefore, though it is possible that the participants' diagnosis could affect the outcome of treatment intervention, it is also possible that intervention could be effective regardless of diagnosis.

The scope and time limitations of this research precluded further in depth analysis of the interactions, beyond the determining factors, between the different sources of data in the study (participant interviews, key informant interviews, the environmental scan, and the Clutter Image Rating Scale ratings by both the participants and key informants).

## ***5.4 Implications of the Study***

### ***5.4.1 Social work practice implications***

Given the pragmatic paradigm used when conducting this research, and my focus on practical strategies for workers to use when working with clients who hoard, a number of social work practice implications can be extrapolated from the findings and discussion. While this section provides recommendations specifically for social work practitioners involved in hoarding cases, other workers can utilize many of these practices. I have divided the practice implications into three sections: utilizing a person-centered, strengths-based perspective; hoarding-informed education and advocacy; and towards a hoarding-informed service for people who hoard.

#### ***5.4.1.1 Utilizing a client-centered, anti-oppressive, strengths-based perspective***

The support of people who hoard must begin by building a solid foundation for a working relationship. The findings of this research echo anecdotal evidence suggested in the literature, demonstrating the need for respect and a non-judgmental, non-confrontational, supportive treatment approach. These findings are consistent with a larger client-centered approach, emphasizing empathy, unconditional positive regard, and genuine respect for the client (Greene, 2008), something that has been widely adopted within social work practice. Given the social stigma faced by people who hoard, this approach is essential in developing rapport and trust between practitioner and client. Furthermore, a social work anti-oppressive practice (AOP) framework will help to ensure that structural inequalities are not reproduced in the relationship between worker and service user in hoarding situations. Indeed Larson (2008) elaborates on the difficulties of implementing an AOP approach in mental health services, and points to a “just working

relationship” and use of “strengths perspectives” as some of the key foundation steps in this process.

The findings of this research as well as the exiting literature demonstrate that the context of the relationship between the worker and the client could affect the overall relationship. While the context of the relationship can be difficult to change (ie. a fire prevention officer will always be a fire prevention officer), the nature of the relationship can be developed through the efforts of the worker. Workers from a variety of fields can utilize strategies of respect, non-judgment, non-confrontation, and supportive treatment to develop rapport, trust and the perception of the person as more than simply a “hoarder”.

Clients may not be receptive to worker involvement, even if practitioners utilize the strategies outlined above. It is important for all workers to understand where a client’s so called ‘resistance to change’ is coming from. The principle of psychological resistance suggests that the more pressure and confrontation a worker puts on the person who hoards, the greater resistance they will face. One of the tenants of motivational interviewing is “roll with resistance” (Miller & Rollnick, 2002, p. 36). The authors explain, “[t]here is also an element here of great respect for the person. What to do about a problem, if anything, is ultimately an individual decision” (Miller & Rollnick, 2002, p. 40). This follows a strengths-based, client-centered approach, which recognizes the client’s need for self-determination. Adopting a non-confrontational, no-pressure approach, particularly for clinical social workers, may prove to be effective for working with individuals who are defensive about their hoarding behaviour. It may not be possible to extend this practice to other workers; given that the role of some housing

workers and code enforcement officers is to delineate limitations, this practice may run contrary to their role.

Similarly, given the client-centered emphasis on client self-determination, practitioners should be cautious of exercising control over hoarding situations. While the literature has clearly outlined the discomfort people who hoard feel when they are not in control of their possessions, my research points to the need for control over eviction or other regulatory processes. In keeping with a client-centered approach, it is important to respect a hoarding clients' capacity for self-determination. By ensuring that all parties involved are clear about what will happen, and ensuring that clients who hoard are able to make informed decisions, clients can then feel some control over the systems within which they must work.

#### *5.4.1.2 Hoarding-informed education and advocacy*

In the preceding section, I have outlined the need for a client-centered, strengths-based approach for service providers working with people who hoard. Awareness of this approach through training and education could promote a more productive relationship between people who hoard and code enforcement or housing workers. However, the physical manifestations of hoarding can look very different from person to person, as can other personal factors, such as the involvement of family, friends, and community support. Tompkins (2015) writes, "no two hoarding situations are the same" (p. 54). Social workers and other service workers involved with hoarding situations need to be aware of this, and strive to practice from a hoarding-informed perspective, understanding the impact of hoarding on different aspects of the client's life.

As outlined earlier in this chapter, neither workers, nor individuals who hoard

were aware of the legalities surrounding human rights and the duty to accommodate. Knowledge about the duty to accommodate could have potentially large ramifications for individuals who hoard in maintaining their tenancies. Awareness of their rights could allow individuals an extended timeframe under which to complete the work that is needed, or allow the support of an outside agency to assist with the physical work. The sole participant who referenced the duty to accommodate was clearly aware that this legal knowledge was key to maintaining her tenancy. While access to affordable legal council is not always a reality, public education and training for individuals who hoard regarding the duty to accommodate could provide people with the language needed to advocate for themselves. The Canadian Association of Social Work's *Code of Ethics* outlines, "Social workers advocate for equal treatment and protection under the law and challenge injustices, especially injustices that affect the vulnerable and disadvantaged" (p.5). Social workers should familiarize themselves with the legalities surrounding hoarding to ensure that the rights of their clients are not being violated.

Similarly, Bratitot et al. (2011) point out, "Failure to use legal interventions appropriately can threaten the civil rights of the person who hoards" (p. 36), highlighting the need for legal education and training for all workers involved in hoarding cases. The careful balance of human rights can not favour any one person or group. Education regarding the limits of worker authority could prove to be beneficial in developing hoarding-informed practices across all professions.

Education among other professions about hoarding may fall to social workers in the community who are responsible for liaising with task forces about hoarding clients. As explored earlier, one fire department has changed the way they write orders,

explaining the changes they require more clearly and explicitly. Perhaps fire prevention and by-law officials could make small changes to their forms in order to make them more “hoarding-friendly”, with clearly defined goals and expectations outlined for the person who hoards. Similarly, social workers could provide education and advocacy to other agencies and services, helping to develop policies and procedures for working effectively with hoarding clients. For example, providing training to landlords regarding the rights of people who hoard, and client-centered strategies to comply with landlord needs.

Likewise, there is a need for social workers and other workers to use proper assessment tools to evaluate hoarding situations holistically, and to determine corresponding services and interventions needed. Bratiotis et al. (2011) provide a wide range of assessment tools available to both clinical and community-based practitioners, some of which are appropriate for use by other workers as well.

#### *5.4.1.3 Toward a hoarding-informed service for people who hoard*

While Waterloo Region is ahead of the curve by employing a full-time person dedicated to supporting and coordinating services for people who hoard, there are still gaps in the services that need to be addressed. Participants and key informants alike noted the dearth of affordable or free deep-cleaning and sorting services for people who hoard; likewise the absence of mental health services has proven to be problematic for individuals who wish to address the psychological and emotional underpinnings of their hoarding problems. Working within these limitations, the Hoarding Project serves the important purpose of not only developing the skills and knowledge of other workers involved in hoarding cases, but also accessing new services within the community. Due to the complexity of hoarding situations and the possibility that many different social

service, code enforcement and housing workers can be involved, no two cases will be alike. Services for people who hoard must be responsive to each unique situation, given the myriad of different stakeholders that can be involved.

Rodriguez, Panero and Tannen (2010) describe a program started in 2009 that provides individualized interventions for people who hoard and are at risk of eviction in New York City. Eviction Intervention Services (EIS) provides both legal and housing advocacy, as well as “a support group, workshops, educational material, referrals to other social services and resources, home visits, emotional support, and individual counselling sessions coordinated by a social worker” (Rodriguez et al., 2010). The program focuses on the client’s preferences, while providing responsive intervention and support on all possible fronts. The outcome has been that none of the 22 individuals who have participated have been evicted, and two have enrolled in psychiatric care (Rodriguez et al., 2010), demonstrating the efficacy of a responsive, individualized program with access to multiple different types of services and supports.

This program demonstrates yet another area in which community social work practice can be affected: in the development of hoarding-informed and coordinated services and programs. Clients could benefit from the integration of multiple services, utilizing the ones best suited to their complex and diverse needs, ultimately helping them to comply with regulations and maintain their housing.



#### ***5.4 Implications for Research and Theory***

Hoarding is an area that has only begun to attract research in the past twenty years or so. Much of the existing research focuses on the epidemiology of hoarding, using a cognitive behavioural framework developed by Frost and Hartl (1996). As such, there are many possible avenues for further research. The pragmatic focus of this study points to six specific areas of study, as outlined below.

1) This research is qualitative and exploratory in nature, and focuses on the experiences of people who hoard. While the preliminary environmental scan gives a sense of the prevalence, further quantitative research is needed to provide statistics as to the prevalence of eviction due to hoarding, as well as the prevalence of hoarding overall in Waterloo Region.

2) As outlined previously, the existing literature about hoarding characterizes people who hoard as “lacking insight” and being resistant to change. I have outlined the concept of defensiveness with respect to hoarding behaviour, and how this can threaten cooperation with regulatory bodies. This concept has been minimally explored and could be important in understanding the reactions of people threatened with eviction or other code enforcement regulations.

3) The findings of this research explore the sense of discrimination felt by participants who hoard. Further exploration on this topic is needed due to the very real problem of stigmatization that results, creating a lack of balance between their rights and the rights of others.

4) The discussion section of this research outlined the legal duty of landlords to accommodate tenants who hoard. While clearly beyond the scope of this research, the

question remains as to whether fire prevention officials are also legally required to provide accommodations, or if safety concerns negate that obligation. Similarly, regulations imposed by condominium corporation by-laws could also be required to provide accommodations for condo owners who hoard. These topics bear further investigation.

5) Anecdotal evidence in both the findings of this study and existing literature suggests that court-mandated treatment for people who hoard is continuing to evolve in both Canada and the United States. However, the effectiveness of court-mandated treatment remains to be seen, and requires more research. Similarly, further research is needed to explore whether court-mandated treatments occur as a result of housing and eviction concerns, fire code violations, child endangerment concerns, or other regulations.

6) The emphasis that participants' put on the relationship with workers led to a potential research inquiry regarding the role of trauma, losses and attachment in hoarding behaviours.

### ***5.5 Impact on the Researcher as a Researcher and Practitioner***

As the researcher, this study has affected me profoundly, changing and shaping not only my ideas about people who hoard, but the people who work with them as well. Prior to starting this project, I had only a cursory knowledge about hoarding. Having listened to teleclasses about hoarding as part of training as a professional organizer, my experience with people who hoard was limited mostly to books and television shows like *Hoarders*. I admit, that as someone who enjoys tidy, organized spaces, much of my interest in hoarding stemmed from how baffling this behaviour was to me. As I

mentioned in the introductory chapter, I received several calls from people seeking help with hoarding problems, and had few suggestions for these callers. Overwhelmed by what I had been told was challenging work, I felt under-qualified and unprepared to work with someone who hoarded.

In preparing my research proposal, I continued to read primarily psychological literature about hoarding. Through my discussions with my supervising committee I became more aware of the pejorative language that surrounds hoarding, particularly with regards to insight and motivation. I wondered whether this was true of people who hoard, and thought back to those phone calls I received, from people concerned about having hoarding tendencies. Certainly some people were aware if or when the behaviour was becoming problematic? As I began to interview the participants, I came to understand what the literature perceives to be lack of insight as a protective factor for some people. The problem can become so overwhelming that it is easier to deny that there is a problem, than to address it.

Brené Brown (2008) summarizes a principle developed by Harriet Lerner, stating that “refusing to take on an identity defined by one’s worst deed is a healthy act of resistance” (p. 65). This rang true to me for the people I interviewed for this research, as well as for myself: what an awful thing, to be defined only by the worst parts of yourself. This seems to be true for people who hoard: once that stigmatized label is thrown out there, it sticks, and all of the negative images perpetuated by both mainstream media and academic literature become the central defining feature of the person. I certainly do not advertise the parts of myself of which I am ashamed or embarrassed. It makes sense that people who hoard would protect themselves in the same way. Ultimately, this

understanding has helped to demystify the so-called lack of insight and motivation at a personal level.

This research has also developed my understanding of my role as a social worker and as an agent of social control. Participants spoke about the intrusiveness of different agencies in their homes and their lives. Likewise, key informants spoke about the understanding that their authority is limited. I realized the need for advocacy for people who hoard, and that this was central to my role as a social worker. Because hoarding is so stigmatized, it is easy for workers involved in hoarding situations to take on a paternalistic role, doing “what is best” for clients, and forgetting that people have a right to choose how they live. This was a shift in perspective for me, too. My assumption was that, given the resources, everyone would choose to live the way that I did, neat and orderly. This has shaped my understanding of my role as a social worker, realizing that part of my role is as an advocate for the people I work with, linking them to the services that serve their goals, not just broader social and cultural goals.

## ***5.6 Conclusion***

This study attempts to re-frame the ways in which we discuss people who hoard from a strengths-based perspective, whereby we highlight and build upon their strengths rather than focus on their deficits. Therefore, people who hoard are given voice in this research. It is my hope that through this research, I have helped to highlight the interactions of people who hoard with social services, code enforcement and housing workers. I have attempted to develop a framework for individuals who work with people who hoard to use as a guide to their conduct, interactions and interventions in order to

prevent eviction. As more programs, task forces, and coalitions continue to develop in communities across Canada, interdisciplinary workers in this field can look to this research to inform their practices. While hoarding behaviours are a relatively new area of academic inquiry, this qualitative study has highlighted a number of areas where further empirical research could be of benefit. Future research must incorporate in depth the perspectives of people who hoard. We must remember always to ask not only *if* we can help, but *how* we can help.

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## APPENDIX A

**Request for Participant Referrals and Information to Agencies, Service Providers  
and Workers**

Hello,

I am conducting an academic study on eviction prevention for people who hoard, and I am seeking participants for this research. The purpose of this study will be to see that factors enable people to maintain their housing when they are at risk of eviction. Through interviews with participants, this study aims to highlight the experiences of people who hoard, and to identify ways in which people who hoard have been able to maintain their housing. This study is part of a graduate social work thesis project, and is in affiliation with Wilfrid Laurier University.

The requirements of participants is that they are currently, or have in the past, been potentially at risk of eviction due to hoarding (accumulated clutter in their homes, resulting in public health concerns, fire code violations, etc.). The outcome of the eviction process may be that they were able to maintain their housing or not. If you are in contact with any individuals who may be a candidate to participate in this study, please give them the attached invitation letter.

The researcher is Emily Gibson, a master of social work student at Wilfrid Laurier University. I have worked as a professional organizer in the private sector, and am respectfully interested in the experiences of people who hoard.

If you have any questions or concerns regarding this study, please do not hesitate to contact me:

Emily Gibson  
[email address]  
[phone number]

Thank you for your contribution to this research through participant referrals!

Best wishes,

Emily Gibson, MSW(c)

## APPENDIX B

### Invitation and Information to Participate in a Study

Hello,

You are invited to participate in a research study. You have been chosen for this research because you have identified that you have been at risk for eviction – now or in the past – because of hoarding.

#### **What is the Research Project About?**

This research project is exploring what has helped to keep your housing when you were at risk of eviction. We will interview 6-8 people who are/have been at risk of eviction and ask them questions about their experiences. We will also interview 6-8 people who work with people who hoard during the eviction process, such as social workers, fire inspectors, property managers, etc., to ask for their perspectives as well.

If you would like to be part of this research, the researcher will arrange to do an interview with you. It will take about one hour to do the interview. The researcher will ask you one main question, and will then ask you to go into detail about specific experiences.

You will also be asked to use a tool called the Clutter Image Rating Scale (CIR) to give the researcher an idea of how much clutter is in your home. The CIR is a series of photos, and you will be asked to choose which photos best represent your home.

This study is a part of a master of social work thesis project and is in affiliation with Wilfrid Laurier University.

#### **Who is doing the research?**

The researcher is Emily Gibson, who is a master of social work student at Wilfrid Laurier University. Before returning to school, Emily worked as a professional organizer. She is concerned about the lack of social services available for people who have hoarding problems, and the impact that this can have on keeping their housing.

Emily is currently completing a 10-week employment contract at Supportive Housing of Waterloo (SHOW) and the Hoarding Project, from June through August 2014. She is working with the Hoarding Project Coordinator, in three different areas:

- 1) Providing support to clients who hoard;
- 2) Working on grant applications to help SHOW secure more grant money for the Hoarding Project;
- 3) Developing policy and procedure manuals for the Hoarding Project.

**THIS RESEARCH PROJECT IS NOT PART OF HER WORK AT SHOW.**

**Whether or not you decide to participate in the research, you will still receive *the same service* from the Hoarding Project.**

**Participating in this research is confidential!**

If you want to participate in the research, this will be confidential: Emily will not let Kim Hodder, SHOW, or anyone else know that you have chosen to do so. If you would like to let Kim know that you are participating, you may do so, only if you choose.

You can get in touch with Emily by phone or email:

Emily Gibson

Email: [email address]

Cell Phone: [phone number]

If you want Emily to call or email you to get in touch, please let Kim know. She will ask you to give her consent to release your name and contact information to Emily.

Once you have connected with Emily, she will arrange a time to meet and you will need to sign a formal consent form to participate. She will also answer any questions you have about the process. You can change your mind if you decide you do not want to participate at any point.

**Thank you for your time and considered contribution.**

Many thanks,

Emily Gibson

Master of Social Work (c)

## APPENDIX C

### **Invitation and Information to Participate in a Study as a Key Informant**

Hello,

You are invited to participate in a research study as a key informant. You have been chosen to participate in this research because you have worked with people who hoard through the eviction process.

#### **What is the research project about?**

The purpose of this study will be to explore, through intensive interviews, about the experience of being potentially at risk of eviction due to hoarding in order to determine what factors are beneficial in maintaining housing. We will interview 6-8 people who have worked with people who hoard, as well as 6-8 people who hoard, to gain their perspectives as well.

If you would like to be part of this research, the researcher will arrange to do an interview with you. It will take about one hour to do the interview. The researcher will ask you one main question, and will then ask you to go into detail about specific experiences. You will also be asked to use the Clutter Image Rating Scale (CIR) to give the researcher a sense of how much clutter is in the homes that you have worked.

This study is a part of a master of social work thesis project and is in affiliation with Wilfrid Laurier University.

#### **Who is doing the research?**

The researcher is Emily Gibson, who is a master of social work student at Wilfrid Laurier University. Before returning to school, Emily worked as a professional organizer. She is concerned about the lack of social services available for people who have hoarding problems, and the impact that this can have on maintaining their housing.

Emily is currently completing a 10-week employment contract at Supportive Housing of Waterloo (SHOW), from June through August 2014. She is working with Kim Hodder, the Hoarding Coordinator, in three different areas:

- 1) Providing support to clients who hoard;
- 2) Working on grant applications to help SHOW secure more grant money for the Hoarding Project;
- 3) Developing policy and procedure manuals for the Hoarding Project.

This research project is not part of her work at SHOW.

If you are interested in finding out more about this study, please contact Emily:

Emily Gibson  
[email address]  
[phone number]

Once you have contacted me, we will arrange a time to meet and to gain your formal consent to participate, and to address any questions you may have about the process.

Thank you for your time and considered contribution to this study.

Best wishes,

Emily Gibson, MSW(c)



## APPENDIX D

**INFORMED CONSENT STATEMENT - PARTICIPANT**

## WILFRID LAURIER UNIVERSITY

**Project Title: Perceptions of Determining Factors:  
A Case Study of Eviction Prevention for People Who Hoard in Waterloo Region**

**RESEARCH TEAM:**

Principal Investigator: Emily Gibson, MSW Student

Advisor: Eliana Suarez, PhD

You are invited to participate in a research study. The purpose of this study is to determine what factors help people who hoard to maintain their housing when they are at risk of eviction. Emily Gibson is the person conducting this research, and it is part of her work as a Master of Social Work student at Wilfrid Laurier University. She will be conducting the interviews and collecting all of the data, as well as writing the final report. Dr. Eliana Suarez, who will be supervising the research, is an Assistant Professor in the Lyle S. Hallman Faculty of Social Work at Wilfrid Laurier University. She will oversee the project and consult with Emily Gibson on the project throughout the process.

**Statement of Conflict of Interest**

Emily Gibson is employed by Supportive Housing of Waterloo (SHOW) for a ten-week period between June and August 2014. She is working directly with people with hoarding problems as part of the hoarding project. You may have received services from SHOW regarding hoarding. If you are working or have worked directly with Emily at SHOW, then you will not be asked to participate in the research. If you have worked with SHOW, but not directly with Emily, the information you disclose about the service that you have received may be used in the final report, but your identity will remain confidential. Emily will not disclose that you are participating in the research to anyone, including the staff at SHOW and the Hoarding Project.

**Information**

Participants have been chosen for this research because they have identified themselves as currently being at risk or having been at risk of eviction because of hoarding. If you have been selected, and would like to participate in this research, the researcher will arrange to do an interview with you. It will take about one hour to do the interview. The researcher will ask you one main question, and will then ask you to go into detail about specific experiences. There will be between 6 and 8 people giving interviews for this research project. In addition, between 6-8 people who work with people who hoard will also be asked to give interviews for this research.

You will also be asked to use a self-assessment tool called the Clutter Image Rating Scale (CIR) to give the researcher an idea of how much clutter is in your home. The CIR is a series of photos, and you will be asked to identify which photos best represent your home.

The interview will be audio recorded with a digital recorder with your permission. You have the right to ask that the audio recorder be turned off at any point, and the researcher will take handwritten notes. The audio recordings are for research purposes only. Only the researcher, and her supervisor will have access to the audio recording. The audio recording will be downloaded onto a password-protected computer and transcribed by the researcher or a transcriber who has taken an oath of confidentiality. The audio recordings will be deleted from the audio recorder and from the computer after they have been transcribed. Information disclosed in the interview will be included in the researcher's master's thesis, although care will be taken to ensure that no identifying information is disclosed.

### **Identification of the Researcher**

The researcher is Emily Gibson, a Master of Social Work student at Wilfrid Laurier University. Emily has worked as a professional organizer to help people with their clutter. She is interested in improving services for people who hoard, and feels strongly that the voices of people who hoard need to be included in developing these services.

### **Risks**

You will be asked to talk about your experiences with eviction or the threat of eviction. You may find that talking about these experiences cause you to feel distressed or upset. In order to minimize the amount of distress that you may feel, the researcher will speak with you about how you are feeling after the interview is complete. The researcher will also provide you with a list counselling services where you can go for further help with distressed feelings.

There is a risk that someone may recognize a specific experience that you describe, and be able to identify that you were one of the research participants. Confidentiality is of the utmost importance in this research. All precautions possible will be taken to ensure that there it is difficult for you to be identified based on what is written in the research report.

The researcher is a master of social work student, and as such may be compelled to disclose your identity if you disclose potential harm to yourself or to someone else.

### **Benefits**

The main benefit in participating in this study is helping the researchers to understand what has helped you not to be evicted from your home. This information can help to develop services and policies for this (and other) municipality and social service agencies. This research will also be adding to the literature about hoarding. You may feel a sense of empowerment and community in helping to shape policies and procedures, and in helping other individuals who are struggling with hoarding and eviction to have a positive outcome.

## **Confidentiality**

### *Interview Location:*

An appropriate location for the interview will be arranged with you – it will need to be somewhere that you are comfortable to speak and somewhere private. Possible options include the offices at Supportive Housing of Waterloo (SHOW), who are community partners in this research, or the Faculty of Social Work building at the Wilfrid Laurier University. If you have confidentiality concerns about the location of the interview, the researcher can work with you to find a place that is appropriate and confidential for you to do the interview.

### *Identifying Information:*

Your name and other identifying information will be kept only on a password-protected computer, and only the research team will have access to this information. Quotations from the interviews will be used in the final thesis report, and as such, there is a possibility that someone could recognize a situation or detail that could identify you. The researcher will take every precaution to edit quotes so that any identifying information is omitted. The researcher will also provide a list of your quotes that will be used in the final report. If you have concerns about your identity being revealed through these quotations, the quote will be altered so that the identifying information is not included, or the quote will not be used. The final report will be printed and kept on file at Wilfrid Laurier University, where others will have access to it.

Once the project has been completed, identifying information will be deleted from the researcher's computer. Transcripts of the interviews will be saved on the researcher's password protected computer for seven years with identifying information removed from them. If the researcher wishes to use this information for future research work, publications or presentations, she will contact you to ensure that no quotations are used without your prior consent.

Confidentiality is of the utmost importance. Although absolute confidentiality can not be guaranteed, the above precautions will limit the risk of confidentiality being broken. Disclosure of information to appropriate services will be only considered in the case of imminent safety risks to self or others.

## **Contact**

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study\*) you may contact the researcher, Emily Gibson, at [email address], and [phone number]. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Robert Basso, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 4994 or [rbasso@wlu.ca](mailto:rbasso@wlu.ca).

**Participation**

Your participation in this study is voluntary, and you may choose to stop participating at any time. If you decide not to volunteer it will not affect your relationship with any of the services for hoarding that you are receiving now, or your relationship with Wilfrid Laurier University, either now or the future. If you choose to withdraw from the study, every attempt will be made to remove your data from the study, and have it destroyed.

If you choose not to answer specific questions during the interview, this will not have an affect on your relationship with the researcher, Wilfrid Laurier University or any other group associated with the project.

**Feedback and Publication**

This research will be used in a master's thesis report at the Lyle S. Hallman Faculty of Social Work at Wilfrid Laurier University. You will be informed once the research is complete and have access to the finished report (the estimated date of completion is March 2015). The researcher will provide you with an executive summary of the findings of the research upon completion. You may choose whether you would like this information emailed to you or a paper copy mailed to you. Findings from this research will be reported in conference presentations and journal articles. Local agencies and/or services where you may receive service may also receive a copy of the report.

**Consent to Participate**

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature \_\_\_\_\_ Date \_\_\_\_\_

Investigator's signature \_\_\_\_\_ Date \_\_\_\_\_

**Audio Recording Consent**

I agree to have my interview audio recorded. I understand that if I select no, the interviewer will take hand-written notes of our conversation and will still use my words in the final report.

Please check one:

☐ Yes

☐ No

Participant's signature \_\_\_\_\_ Date \_\_\_\_\_

Investigator's signature \_\_\_\_\_ Date \_\_\_\_\_

**Reviewing Quotes Before Use**

I understand that my words may be quoted in this research paper. The researcher will remove any identifying information so that my identity will not be known to others reading the final report.

I would like to review the quotes that the researcher will be using in the final report and make any changes necessary to protect my identity.

Please check one:

☐ Yes

☐ No

Participant's signature \_\_\_\_\_ Date \_\_\_\_\_

Investigator's signature \_\_\_\_\_ Date \_\_\_\_\_

If “Yes”, I would like the researcher to send me the quotes by:

☐ Mail to the following street address:

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☐ E-mail to the following e-mail address \_\_\_\_\_

## APPENDIX E

**INFORMED CONSENT STATEMENT – KEY INFORMANTS****WILFRID LAURIER UNIVERSITY**

**Project Title: Perceptions of Determining Factors:  
A Case Study of Eviction Prevention for People Who Hoard in Waterloo Region**

**Research Team:**

Principal Investigator: Emily Gibson, MSW Student

Advisor: Eliana Suarez, PhD

You are invited to participate in a research study. The purpose of this study is to determine what factors help people who hoard who are at risk of eviction to maintain their housing. Emily Gibson is the person conducting this research, and it is part of her work as a Master of Social Work student at Wilfrid Laurier University. She will be conducting the interviews and collecting all of the data, as well as writing the final report. Dr. Eliana Suarez, who will be supervising the research, is an Assistant Professor in the Lyle S. Hallman Faculty of Social Work at Wilfrid Laurier University. She will oversee the project and consult with Emily Gibson on the project throughout the process.

**Conflict of Interest**

Emily Gibson is employed by Supportive Housing of Waterloo (SHOW) for a ten-week period from June to August 2014. You may have worked with SHOW regarding a client who hoards. If you have worked with SHOW, the information you disclose may be used in the final report, but your identity will remain confidential. The researcher will not disclose that you are participating in the research to anyone, including the staff at SHOW, without your consent.

**Information**

Key informants have been chosen for this research because they have worked with people who hoard. If you have been selected, and would like to participate in this research, the researcher will arrange to do an interview with you. It will take about one hour to do the interview. The researcher will ask you one main question, and will then ask you to go into detail about specific experiences. You will not be asked to identify the people with whom you have worked or break confidentiality with them – nor should you volunteer this information. There will be between 6 and 8 key informants giving interviews for this research project. Between 6-8 people who hoard will also be asked to give interviews for this research project.

You will also be asked to use an assessment tool called the Clutter Image Rating Scale (CIR) to give the researcher an idea of how much clutter is in the homes that you are working or have worked in. The CIR is a series of photos, and you will be asked to identify which photos best represent the homes that you have worked in. The researcher will not ask you to identify specific homes, but to give a general sense of how much clutter is in the different homes.

If you work for a property management company or are the landlord or superintendent of a large, multi-unit tenancy, the researcher will ask you how many tenants you have in your building who are hoarding, and how many are at risk of eviction because of hoarding. The researcher will ask for the numbers by year, for this year and the past five years.

The maximum time it would take to for you to participate in this research is approximately two hours. The amount of time it will take will depend on how much you will disclose in the interview.

The interview will be audio recorded with a digital recorder with your permission. You have the right to ask that the audio recorder be turned off at any point, and the researcher will take handwritten notes. The audio recordings are for research purposes only. Only the researcher and her supervisor will have access to the audio recording. The audio recording will be downloaded onto a password-protected computer and transcribed by the researcher or by a transcriber who has taken an oath of confidentiality. The audio recordings will be deleted from the audio recorder and from the computer after they have been transcribed. Information disclosed in the interview will be included in the researcher's master's thesis, although care will be taken to ensure that no identifying information is disclosed.

### **Identification of the Researcher**

The researcher is Emily Gibson, a Master of Social Work student at Wilfrid Laurier University. Emily has worked as a professional organizer to help people with their clutter. She is interested in improving services for people who hoard, and feels strongly that the voices of people who hoard need to be included in developing these services.

### **Risks**

You will be asked to talk about your experiences in working with people who hoard who are at risk of eviction. You may find that talking about these experiences cause you to feel distressed or upset. In order to minimize the amount of distress that you may feel, the researcher will debrief with you after the interview is complete. The researcher will also provide you with a list of resources, including counselling services, where you can go for further help with distressed feelings.

Confidentiality is of the utmost importance in this research. All precautions possible will be taken to ensure that there it is difficult for you to be identified based on what is written in the research report. However, this is still risk in that someone may recognize a specific situation that you describe, and be able to identify that you were one of the key informants.

The researcher is a master of social work student, and as such may be compelled to disclose your identity if you disclose potential harm to yourself or to someone else.

## **Benefits**

The main benefit in participating in this study is helping the researchers to understand what has prevented people who hoard from being evicted from their homes. This information can help to develop services and policies for this (and other) municipality and social service agencies. This research will also be adding to the literature about hoarding. You may feel a sense of empowerment in helping to shape policies and procedure, and in helping other individuals who are struggling with eviction due to hoarding to have a positive outcome.

## **Confidentiality**

### *Interview Location:*

An appropriate location for the interview will be arranged with you – it will need to be somewhere that you are comfortable to speak and somewhere private. Possible options include your current place of employment, provided that there is access to a private room; Supportive Housing of Waterloo (SHOW), who are community partners in this research; or the Faculty of Social Work building at the Wilfrid Laurier University. If you have confidentiality concerns about the location of the interview, the researcher can work with you to find a place that is appropriate and confidential for you to do the interview.

### *Identifying Information:*

Your name and other identifying information will be kept only on a password protected computers, and only the research team will have access to this information. Quotations from the interviews will be used in the final thesis report, and as such, there is a possibility that someone could recognize a situation or detail that could identify you. The researcher will take every precaution to edit quotes so that any identifying information is omitted. The researcher will also provide a list of your quotes that will be used in the final report. If you have concerns about your identity being revealed through these quotations, the quote will be altered so that the identifying information is not included, or the quote will not be used. To minimize the possibility of this occurring, key informants will have the opportunity to review quotations being used in the report, and dictate that they be altered or removed. The final report will be printed and kept on file at Wilfrid Laurier University, where others will have access to it.

Once the project has been completed, identifying information will be deleted from the researcher's computer. Transcripts of the interviews will be saved on the researcher's password protected computer for seven years with identifying information removed from them. If the researcher wishes to use this information for future research work, publications or presentations, she will contact you to ensure that no quotations are used without your prior consent.

Confidentiality is of the utmost importance. Although absolute confidentiality can not be guaranteed, the above precautions will limit the risk of confidentiality being broken. Disclosure of information to appropriate services will be only considered in the case of imminent safety risks to self or others.



### **Contact**

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study) you may contact the researcher, Emily Gibson, at [email address], and [phone number]. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Robert Basso, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 4994 or rbasso@wlu.ca.

### **Participation**

Your participation in this study is voluntary, and you may choose to stop participating at any time. If you decide not to volunteer it will not affect your relationship with our community partner, Supportive Housing of Waterloo, or your relationship with Wilfrid Laurier University, either now or the future. If you choose to withdraw from the study, every attempt will be made to remove your data from the study, and have it destroyed.

If you choose not to answer specific questions during the interview, this will not have an affect on your relationship with the researcher, Wilfrid Laurier University or any other group associated with the project.

### **Feedback and Publication**

This research will be used in a master's thesis report at the Lyle S. Hallman Faculty of Social Work at Wilfrid Laurier University. You will be informed once the research is complete and have access to the finished report (the estimated date of completion is March 2015). The researcher will provide you with an executive summary of the findings of the research upon completion. You may choose whether you would like this information emailed to you or a paper copy mailed to you. Findings from this research will be reported in conference presentations and journal articles.

### **Consent to Participate**

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature \_\_\_\_\_ Date \_\_\_\_\_

Investigator's signature \_\_\_\_\_ Date \_\_\_\_\_

**Audio Recording Consent**

I agree to have my interview audio recorded. I understand that if I select no, the interviewer will take hand-written notes of our conversation and will still use my words in the final report.

Please check one:

☐ **Yes**

☐ **No**

Participant's signature \_\_\_\_\_ Date \_\_\_\_\_

Investigator's signature \_\_\_\_\_ Date \_\_\_\_\_

**Reviewing Quotes Before Use**

I understand that my words may be quoted in this research paper. The researcher will remove any identifying information so that my identity will not be known to others reading the final report.

I would like to review the quotes that the researcher will be using in the final report and make any changes necessary to protect my identity.

Please check one:

☐ **Yes**

☐ **No**

Participant's signature \_\_\_\_\_ Date \_\_\_\_\_

Investigator's signature \_\_\_\_\_ Date \_\_\_\_\_

If “Yes”, I would like the researcher to send me the quotes by:

☐ Mail to the following address:

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☐ Email to the following e-mail address:

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## APPENDIX F

### Interview Guide – Participants

#### Grand Tour Question:

When you are or have been at risk of eviction, could you tell me what have enabled you to maintain your housing?

- Please describe your current situation
  - Are you currently at risk of being evicted?
    - What does the landlord/property manager say is the problem?
    - What's your perspective on this?
- Were you previously at risk of eviction?
  - How many times?
  - Describe the past situation(s)
- What things have you done/did you do to stop from being evicted?
  - Probes:
    - Clear clutter or discard items
    - Look/find for social supports
    - Look/find for social services
    - Look/find for medical treatment
    - Find/look for legal representation
- What was the eviction threat the result of?
  - Code violations
  - Deterioration of the home/apartment unit
  - Not being able to pay rent/financial trouble
- What else was/is going on in your life at the time of eviction?
  - What were the circumstances leading up to the eviction notices?
  - Stressful life situations, etc.

#### Experience

- What did you think about the eviction notices?
  - Unfair
  - Reasonable
- How did you feel when you received the eviction notices/found out that there was a threat of eviction?
- What was the experience of discarding possessions like for you?
- What was it like to work with the various different agencies that you were in touch with throughout this process?
  - What was their treatment towards you like?

#### Involvement of Other Parties

- What professional services are/were you involved with?
  - Code enforcement (fire/public health/building inspectors)

- Social workers
- Counsellors/therapists
- Doctors/psychiatrists
- Landlord/property manager/superintendent
- Professional organizers/cleaning companies
- Who else was involved in the situation, more informally?
  - Friends/family/neighbours
  - Church/religious groups/leaders (minister, rabbi, imam etc.)
- What services were you initially in touch with?
- What services did the initial workers refer you to?
- What services were you referred to but you did not follow up on or accept help from?
- What sorts of things did these people do? What role did they have?
- What has been helpful to you?
  - Having items discarded?
  - Having someone sort through items with you?
  - Having a support person to talk to about the situation?
  - Having a deadline for completing tasks?
  - Having someone to keep you on task?
- What was not helpful or hurtful?
  - Having items discarded?
  - Having someone sort through items with you?
  - Having a support person to talk to about the situation?
  - Having a deadline for completing tasks?
  - Having someone to keep you on task?
- What could the other people you worked with in this process have done differently?
  - Treatment of you as a person
  - Attitude towards the situation/you as a person

### Outcomes

- What was the outcome or current status of your eviction?
  - Resolved
  - Evicted
  - Continued inspections
- What would you have done differently if you were to go through this process again?
- What advice would you have for someone else who hoards going through this process?
- How did you feel about the eviction and/or clearing/discarding process after you had been through it?

Note: Sub-bullet points indicate probes in the event that participant has difficulty answering questions.

## APPENDIX G

### Interview Guide – Key Informants

#### Grand Tour Question:

When at risk of eviction, what has helped people who hoard to maintain their housing?

- Please describe the situation(s) that the person(s) were in
  - If 3 or less cases, ask them to talk about each individual situation
  - If more than 3 cases, ask them to pick a few experiences to highlight, but can also answer the questions generally from their overall experience.
- What was the eviction threat the result of?
  - Code violations
  - Deterioration of the home/apartment unit
  - Not being able to pay rent/financial trouble
- Have you been involved in helping someone who hoards maintain their housing?
  - How many times have you been in this role?
- Have you been involved in the eviction process with someone who hoards?
- What was your role?
  - Support worker
  - Code enforcement
  - Social services
- What types of things did you do?
  - Make referrals to other services
  - Clear out clutter/possessions
  - Connect person with friends/family/other social supports
  - Provide emotional support to person
- What policy or rules does your agency/workplace have about working with people who hoard?
  - Formal or informal
  - Rules or procedures
  - Experience working with people who hoard previous to this?
- When was this?
- How long did the process take?
  - Days, weeks, months, years
- What was the outcome?
  - Eviction/no eviction
  - Changed relationship with the individual
  - Change in individuals hoarding behaviours (reduced/increased)

#### Personal Experience(s)

- How did you feel about the process?
  - (Un)ethical or (un)fair to the person?
  - Moved to slowly/quickly?
  - Frustrating/empowering

- How did you feel about your role in the process?
  - Felt as though had done all you could?
  - Frustrated that there were not more supports?
  - Disempowered to do anything or ineffective?
  - Role was too punitive? Or not enough?
- If you were to go through this process again with someone who is hoarding, what would you do differently?
- How did you feel about working with the person?
  - Frustrated by lack of insight?
  - Felt sympathy/compassion for them?
  - Disgust at state of home or behaviour?
- What supports or referrals did you make to the person you were working with?
  - F&CS
  - SPCA/Humane Society
  - Counselling services
  - Elder abuse hotline
- What other agencies or code enforcement people did you call or refer to?
  - Fire code
  - Public health
- What impact did the experience have on you?
  - Changed the way you thought about hoarding?
  - Saw systems for eviction in a different light?
  - Grateful for your own mental health?

#### Experience with Person Who is Hoarding

- What was the reaction of the person that you were working with towards your involvement?
  - Hostile
  - Grateful
  - Indifferent
  - Avoidant
- What was your impression of the experience of the person you were working with?
  - Traumatized or upset
  - Grateful for help
  - Positive
- What was your impression of the impact that the experience had on the person you were working with?
  - They changed their hoarding behaviour? Got better or worse?
  - Re-connected or disengaged with family/friends/social supports?
  - Became more mistrustful or open towards social services/code enforcement/landlords?
- What were the things that helped the person the most?
  - Referrals to services
  - Connection to other people
  - Code enforcement threats

- Removal of their possessions
- What were the things that helped the person the least?
  - Code enforcement threats
  - Referrals to services
  - Connection to other people
  - Removal of their possessions

Note: Sub-bullet points indicate probes in the event that key informant has difficulty answering questions.

## APPENDIX H

## Counselling and Distress Services in Waterloo Region

**KW Counselling Services**

Walk-in counselling available 12pm-6pm every Thursday (no appointment necessary)

519-884-0000

480 Charles St. East

Kitchener, ON N2G 4K5

<http://www.kwcounselling.com>

Hours of Operation

Monday – Thursday: 8:30AM to 8:00PM

Friday: 8:30AM – 5:00PM

Saturday & Sunday: Closed

**Carizon Family & Community Services (formerly Mosaic)**

Counselling services available

(519) 743-6333

400 Queen Street South

Kitchener, ON N2G 1W7

<http://www.mosaiconline.ca>

Hours of Operation

Monday – Thursday: 8:00AM to 9:00PM

Friday: 8:00AM – 5:00PM

Saturday: 8:00AM – 4:00PM

**Canadian Mental Health Association****Distress Hotline**

519-745-1166

Available 24 hours a day, 365 days a year



## Clutter Image Rating Scale (CIR)

### Clutter Image Rating Scale: Kitchen

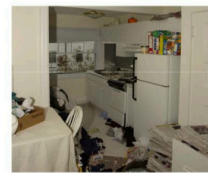
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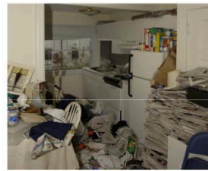
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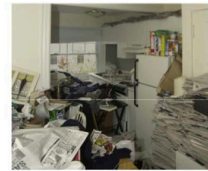
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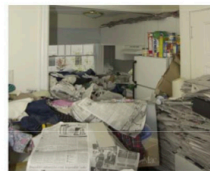
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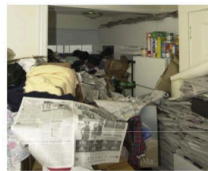
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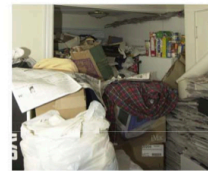
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7



8



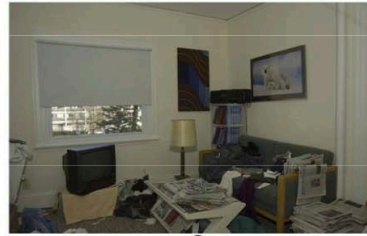
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## Clutter Image Rating: Living Room

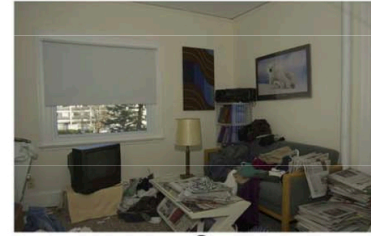
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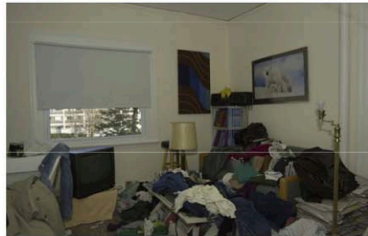
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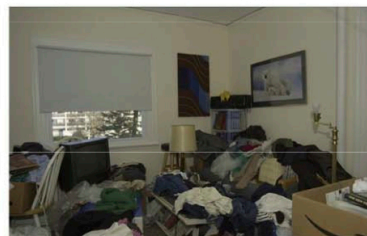
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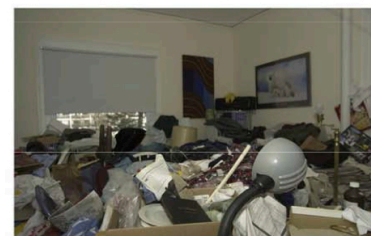
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4



5



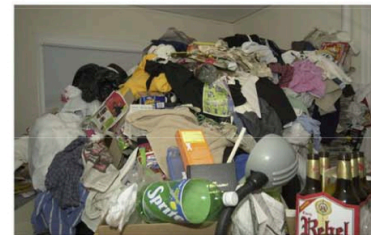
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7



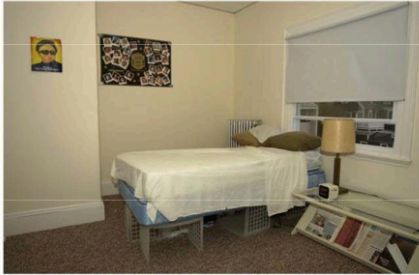
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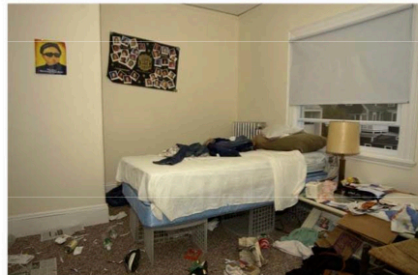
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## Clutter Image Rating: Bedroom

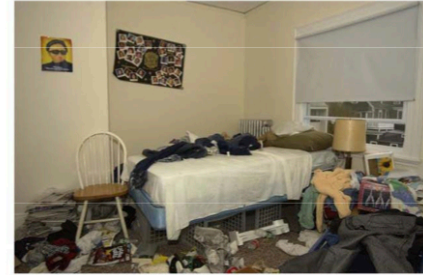
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1



2



3



4



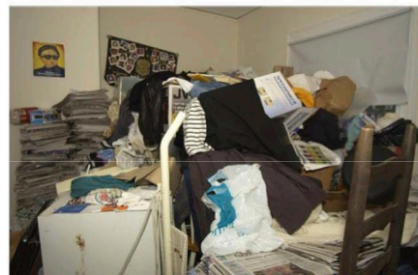
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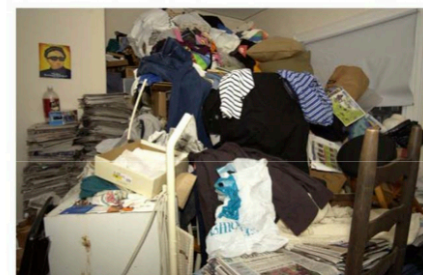
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7



8



9